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SELF-MANAGEMENT AND SELF-EFFICACY ACROSS THE MULTIPLE SCLEROSIS JOURNEY

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A thesis submitted in partial fulfilment of the requirements of the University of Northumbria at Newcastle for the degree of Doctor of Philosophy

Research undertaken in the School of Health, Community and Education Studies.

October 2009

Declaration

I declare that the work contained in this thesis has not been submitted for any other award and that it is all my own work.

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Abstract

Multiple Sclerosis (MS), the most common progressive neurological disease in young adults, can take a relapsing remitting (RR) course especially in the early stages. There is a gap in knowledge in the application of knowledge to self-management and self-efficacy with progressive long-term conditions. This research explored the experience of individuals with RRMS in particularly focusing on their attitudes to self-management and the development of self-efficacy. The research addressed the question about engagement with self-management and self-efficacy influencing the journey of people with RRMS and their formal and informal carers.

The research draws on the experiences, perspectives and understanding of the social processes and perceived reality through interaction. Using grounded theory for generation of the themes identified from responses from people with RRMS, their partners/carers and professionals involved in their care. The research was designed using longitudinal studies exploring the experiences of people with RRMS and their partners/carers, through participation in individual interviews over eight meetings held monthly. The research sample of people with RRMS was three male and three female with an average age of 44.5 years, a mean duration with RRMS for 9.6 years. Professionals who were recruited through purposive theoretical sampling shared their perceptions and experiences through a focus group and individual interviews. Personal and reflective diaries were kept by the researcher of events throughout the study enabling decision and audit trails to contribute to the rigour of the research. The data analysis has generated a number of themes that have been developed and presented throughout the thesis.

The research process has generated new theory around the knowledge of and experiences of the three groups, who are people with RRMS, their partners/carers and professionals involved in their care, of research participants. Fluctuations of living with RRMS across turbulent roller coaster journeys, with transitional processes of daily changes and meanings brought threats and challenges. These highlight the importance of self-efficacy and self-control, of coping with uncertainty and unpredictability, through engaging with self-management behaviours. These enhanced perceptions of self-determination, self-control, positiveness, independence, quality of life and well-being. The transformation of uncertainty secured hope, opportunities and embracing RRMS through coping mechanisms and increased self-confidence. Formal and informal support was required where the people with RRMS deemed appropriate. The key message from this research was that people with RRMS go through a process of phases of integration through changing their world with new understandings, beliefs and the importance of engaging with self-management and self-efficacy while endeavouring to reach outcomes of maintaining independence, self-control, positiveness, mastery and quality of life.

Implications for practice, policy and further research were derived from the conclusions. In practice more empowerment, communication, advice and information are required for people with RRMS to live independently. Policies for skills and knowledge training in these areas are required for shared decision-making, choice and partnership working. Further research is required into utilisation of Integrated Care Management of ways of supporting independence, self-control and personalised plans for people with long-term conditions and their informal carers. The three groups of research participants did have determination, purpose, willingness and ability to work together but each had differing agendas, understanding and no mutual goal to promote and support engagement with self-management and self-efficacy across the RRMS journey.

Self-management and Self-efficacy across the Multiple Sclerosis Journey - Route Map

Overview of PhD Thesis

Multiple Sclerosis is the most common disabling neurological disorder affecting young adults and around 100,000 people in the UK have MS

Self-management and Self-care is advocated for People with MS

In order to see if this is realistic and what the People with MS want – more information is required about the experiences of People with RRMS

This indicates an open-ended approach is needed to allow data collection without assumptions

This suggests qualitative research

Grounded theory constructivist methodology with methods of unstructured interviews, focus groups, longitudinal studies, reflective personal diary

Data generation, analysis and evaluation to determine the main themes of the RRMS unpredictable trajectory

Contribution to knowledge through addressing theory, practice and reality.

Acknowledgements

There are many people to whom I owe a debt of gratitude in completing this research study. I thank my academic supervisors whose guidance and professionalism was a major impetus for me: Doctor Susan Carr (Principal Supervisor) and Professor Jan Reed who both motivated and inspired me at every stage and gave me time in their busy schedules and generously shared their extensive knowledge and expertise. I thank them for their patience and skilled mentorship, encouragement and wisdom, for kind and constructive comments on my drafts and for helping to ensure I completed the project on time. Also Doctors Anna Jones and Glenda Cook for their support and time in undertaking my mock viva.

I thank the people with RRMS, their partners and carers and the health and social care professionals who participated in the research study. They gave their time and freely shared with me their knowledge and experiences of living and coping with RRMS. They welcomed me into their homes, shared their journeys and spent much time with me contributing to my research. I do hope that the outputs from this research will contribute to increased understanding of their worlds of RRMS.

I also thank many colleagues for: encouragement; supporting my time to help me complete the project; friendship and humour; technical and administration support. In particular, these include; Doctor Colin Chandler, Doctor Gill Gillespie, Lorna Kennedy, Julie Blackwell and all other staff. Professor Vivien Hollyoak and Lyn Dixon from North Tyneside PCT and also all the other PhD students who also gave me peer support and friendship as we all kept each other going.

Of course I would also like to thank my family and friends for their interest, wise words and support, in particular my sister Phil. Most importantly, I would like to thank my husband Bill, for his loving support, patience and unfailing belief in my ability to complete this study.

Table of Contents

Abstract	III
Overview of PhD Theses – Route Map.....	IV
Index and Prologue	VI
 Chapter One: Setting the Scene	 1
Background to the Research Study	2
Rationale for the Research Study	7
Presentation of the Thesis with Chapters Outlined	11
 Chapter Two: Theoretical Perspectives	 15
The Literature Review.....	20
Dimensions and impact of engagement with self-management	21
Experiences of engagement with self-management and self-efficacy	34
Influences of engagement with self-management and self-efficacy	45
Conclusions.....	59
 Chapter Three: Theoretical Framework	 61
Research Aims	61
Social Constructionism.....	66
Interpretivism.....	68
Symbolic Interactionism	69
Grounded Theory	72
Sampling in Grounded Theory	77
Role of the Researcher	87
Conclusions.....	91
 Chapter Four: Methods used in the study	 93
The Research Design	93
Methods Used	94
Focus Groups.....	94
Longitudinal Studies	96
Semi-structure Interviews	98

Self-efficacy Qualitative Questionnaire.....	99
Personal and Reflective Diaries	102
Research Phases.....	104
Conclusions.....	108
Chapter Five: Data Analysis	109
Data Analysis and Evaluation	115
Coding and Categorising the Data	116
Computer assisted data analysis	126
Summary of analysis of self-efficacy scores	128
Theoretical Saturation	141
Co-construction of meaning in qualitative research	142
Conclusions	144
Chapter Six: Challenge.....	146
The Roller Coaster of RRMS	146
Challenge of Self-Identity	147
Challenge of Disavowal or Denial	160
Theoretical Linkages: The Trajectory Framework	165
Conclusions.....	170
Chapter Seven: Transition	172
Engagement in transitions	174
Uncertainty and unpredictability	175
Ability and willingness to self-Manage	181
Engagement with self-management of RRMS	187
Conclusions.....	190
Chapter Eight: Transformation	192
Empowerment, encouragement and support.....	195
Self-efficacy.....	201

Engagement and disengagement	203
Partnership working and social networking	206
Vision for the future	209
Theoretical understandings	210
Quality of life	213
Conclusions.....	215
Chapter Nine: Discussions and Conclusions.....	217
Aims of the Study.....	219
Uncertainty and unpredictability in RRMS	223
Power Relations	235
Autonomy and Control over the Support Required.....	240
Self-Efficacy in RRMS	245
Coping Strategies.....	246
Contribution to Knowledge and Understanding	251
Implications for Practice	253
Implications for Policy.....	257
Recommendations for Further Research	260
Final Conclusions.....	261

Figures, Tables and Appendices

Figure 1.1 Conceptual Framework.....	5
Figure 2.1 Subject Relevance Tree Literature Review.....	17
Figure 2.2 Biopsychosocial Paradigm.....	47
Figure 2.3 Chronic Care Model.....	54
Figure 3.1 Research Methodologies Decision Making Tree	64
Figure 3.2 Research Methods Decision Making Tree	65
Figure 4.1 Framework for the Research Process	95
Figure 4.2 MS Journey Map – exploring routes	97
Figure 4.3 Question Areas of Self-Efficacy	101
Figure 4.4 Research Data Collection.....	107
Figure 5.1 The Roller Coaster of RRMS	121
Figure 5.2 MS Journey Map with Themes	122
Figure 5.3 Research Themes Criteria.....	123
Figure 5.4 Bubbling Funnel.....	124
Figure 8.1 Engagement with Self-Management.....	205
Figure 9.1 Possible Areas for further Exploration	222
Figure 9.2 Theoretical Concepts Explored.....	225
Figure 9.3 Adaptation of the Stress/Coping Model	231
Figure 9.4 Theory of Planned Behaviour Model	249
Figure 9.5 Balance between Dependence and Independence	256
Figure 9.6 Theoretical Basis of Research Conclusions	259

Figure 9.7 Summary of Research Project.....	265
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Tables

Table 3.1 Sampling Strategy of People with MS.....	78
Table 3.2 Actual Sample of People with RRMS.....	84
Table 3.3 Sampling Frame of People with RRMS	85
Table 7.1 Common MS symptoms classified as ‘visible’ or ‘invisible’	189
Table 8.1 The Process of Empowerment.....	198
Table 9.1 Theory of Planned Behaviour	250

Appendices

Appendix I Self-Management Support.....	267
Appendix II Ethics Information	271
Appendix III Research Interview Topic Guides	288
Appendix IV Data Analysis Processes – Data Examples.....	293
Appendix V Self-Efficacy Questionnaire and Analysis	302
Appendix VI Personal Journey Maps of People with RRMS	372

References

List of References.....	379
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Prologue

My motivation for this research was my professional and personal experiences of patients and friends who have lived with chronic illnesses where assumptions were made around how they could cope with all aspects of their lives with little or no support. The research is important because Government policy makers are stressing the importance of involving patients in self-management and self-care with support of their families in the provision of care management and integrating them as part of formal systems of health and social care delivery. Therefore the concepts of self-management and self-efficacy of LTCs were chosen as areas to further explore.

The aim of the PCT and Council is to improve the rate of early diagnosis of LTCs, helping individuals to manage their own condition as far as possible and to support them with personalised care, including access to advice from community matrons and specialist services.

Long Term Conditions Strategy, Northern PCT, July 2005.

The PCT were particularly interested in the research involving the Neurological Rehabilitation Team (NRT) and following discussions with the team, I chose the progressive long term neurological condition of Multiple Sclerosis as my research condition. During discussions with the NRT and people with MS it became increasingly apparent that MS had an immense impact on many aspects of the lives of the people with MS, their partners /carers and the health and social care professionals. People with MS face huge challenges that require exploration, explication and understanding by all the people who should be involved in providing support to them. It also became clear that the experiences of people with MS with self-management had not been previously described or rigorously explored in this area so there was a gap in the knowledge. I also became convinced that there were deficits in the knowledge of the experiences of these three groups of people in the self-management of this complex, unpredictable condition and that greater

insights could improve the MS trajectory. These provided an opportunity for an original contribution to the field of study.

From the onset I was determined that the gaps in knowledge and experiences between the people with MS, their partners/cares and health and social care professionals could be addressed to lead to the possibility of a smoother more integrated MS journey. This research provides evidence of ways this can be achieved but there is still much to be done to implement improvements. The journeys of 6 people with RRMS go through their MS trajectories supported by their formal and informal carers. The journey is a way to understand how 6 people and their partners/carers engaged with their professional carers to enhance their own self-management and self-efficacy. In order to understand the routes of their journeys and their experiences along the way in their everyday lives, the findings will provide understanding of a small part of their much larger storyline. The storyline will be creating meanings through the use of metaphors and storytelling building up across their RRMS journey and sharing their lived experiences.

This thesis sets out the three year research pathway which has been a remarkable personal journey which has contributed so much to own development and my desire to understand more about living with multiple sclerosis and the coping mechanisms that these people have to remain so positive throughout their MS trajectories. The thesis will describe this journey in considerable depth and begins with Chapter one which sets out the purpose and background of the research study including the pathway through the rest of the thesis.

***“If you bite MS
it bites you back
but it has
sharper teeth than you”
David, MS 6.***

Chapter One: Setting the Scene

Introduction

The growing burden of LTCs has exposed significant limitations in dominant models of care delivery which are reactive, curative and focused on acute, episodic illness. The current healthcare delivery systems are being challenged as they focus on the treatment aim of returning to normal. The overarching purpose of this research study was to find out about life and living with relapsing remitting multiple sclerosis (RRMS) and to use that knowledge and experience to explore the process and conceptual theory of engagement with self-management and self-efficacy of people with RRMS. The research process has generated new theory in finding that people with RRMS go through a process of phases of integration through changing their world with new understandings, beliefs and the importance of engaging with self-management and self-efficacy while endeavouring to reach outcomes of maintaining independence, self-control, positiveness, mastery and quality of life. This new theory came from the knowledge and experiences of people with RRMS, their partners/carers and the health and social care professionals working in this field. This knowledge can be used to inform policy, practice and reality. The social reality of the research participants has been explored in terms of how these relate to engaging and feeling empowered in being involved in self-management and self-efficacy of their RRMS and optimising their quality lifestyle.

Multiple Sclerosis (MS) is the most common disabling neurological disorder affecting young adults. There are an estimated 100,000 people with MS in the UK and most will have been diagnosed between the ages of 20 and 40. Most people (80%) have RRMS where they have relapses (or attacks / exacerbations) followed by periods of remission where symptoms disappear completely or almost completely. Some of these people go on to develop secondary progressive MS where the recovery between relapses may not be as complete and there is a steady increase in disability over time. The people with RRMS are the ones with more physical ability to be involved in self-management and self-efficacy and they are the group of people who are

involved in this research study. The research will describe the RRMS trajectory as going through a journey in engaging and accommodating the condition.

The initial chapter will provide an overview of the background to the study and the content of the chapters to follow, in order to begin the MS journey with an understanding across the continuum of self-management and self-efficacy as perceived by people with RRMS and their formal and informal carers.

Background to the research study

There is international evidence that self-management and self-efficacy are the key drivers of healthcare policy and government priority due to the changing burden of disease and increasing prevalence of all LTCs. Medical advances, technology and population ageing have combined to make LTCs one of the major challenges for healthcare systems, now and in the future. With LTCs the patient's life is irreversibly changed and neither the disease nor its consequences are static. Yet according to Glasgow et al (2003) self-management is the least implemented and most challenging area of chronic disease management. There is a gap in knowledge around the application of self-management and self-efficacy as applied to people with LTCs, especially with people with progressive neurological conditions such as RRMS, which have no cure. The application of self-management and self-efficacy applied to LTCs need to be understood in order to explore how effective they can be to people with progressive LTCs. The research presented in this thesis represents a qualitative paradigm guiding the study, of the voices of people with RRMS and those who support them both formally and informally, with the hope that the knowledge presented will smooth the future transitional journey of the MS trajectory.

Throughout the thesis the reader is provided with signposting of the journey through descriptions and theoretical explanations of what it is like to go through the MS trajectory from the three perspectives of the people with MS, their partners/carers and the professionals. The research has provided new knowledge and understanding of the values of each of the three groups

around the MS journey and has identified the gaps between them with possible solutions to bridge them. The thesis is presented in such a way as to facilitate the reader to move easily through the text in a logical manner. This should enable them to move through the chapters with ease in building up the storylines and the emerging theoretical framework evolving with the research and the data. The conceptual framework in Figure 1.1 provides a focus to the study and place boundaries around the areas being reviewed in order to make the research manageable over the three year period.

Policy Frameworks

Given the long term nature of these conditions, governments and health and social care providers are engaged in initiatives to develop new ways of supporting people who live with LTCs, to be more involved in their own health. The competition for resources between people with acute, curable needs, and those with enduring health problems results in what WHO (2004) refer to as the “Failure of Healthcare” to provide for the growing numbers of people with LTCs. They attribute this failure to the fragmented, acute organisation of care provision that offers only sporadic follow-up, the lack of emphasis on patient’s experience and role in management, the lack of investment in community services, and the prevention of LTCs. There has been a plethora of Government publications including policy and guidance documents produced to support self-management and develop self-efficacy of people with LTCs. However, many of them are too generic and focused on resource management, targets to reduce utilisation of acute care and more effective use of primary care support for self-care; rather than uncoordinated, fragmented and duplicated care processes. The NHS Improvement Plan (DH 2004d) and Supporting People with Long Term Conditions (DH 2005e) however have set out plans to help people with LTCs live healthier, more independent and better quality lives to improve their standards of living and general well-being. Yet there is a lack of implementation and monitoring plans for the application of macro level health and social care policies.

The importance of supported self-management and self-efficacy of the roles of people with LTCs and their partners/carers being involved in the planning,

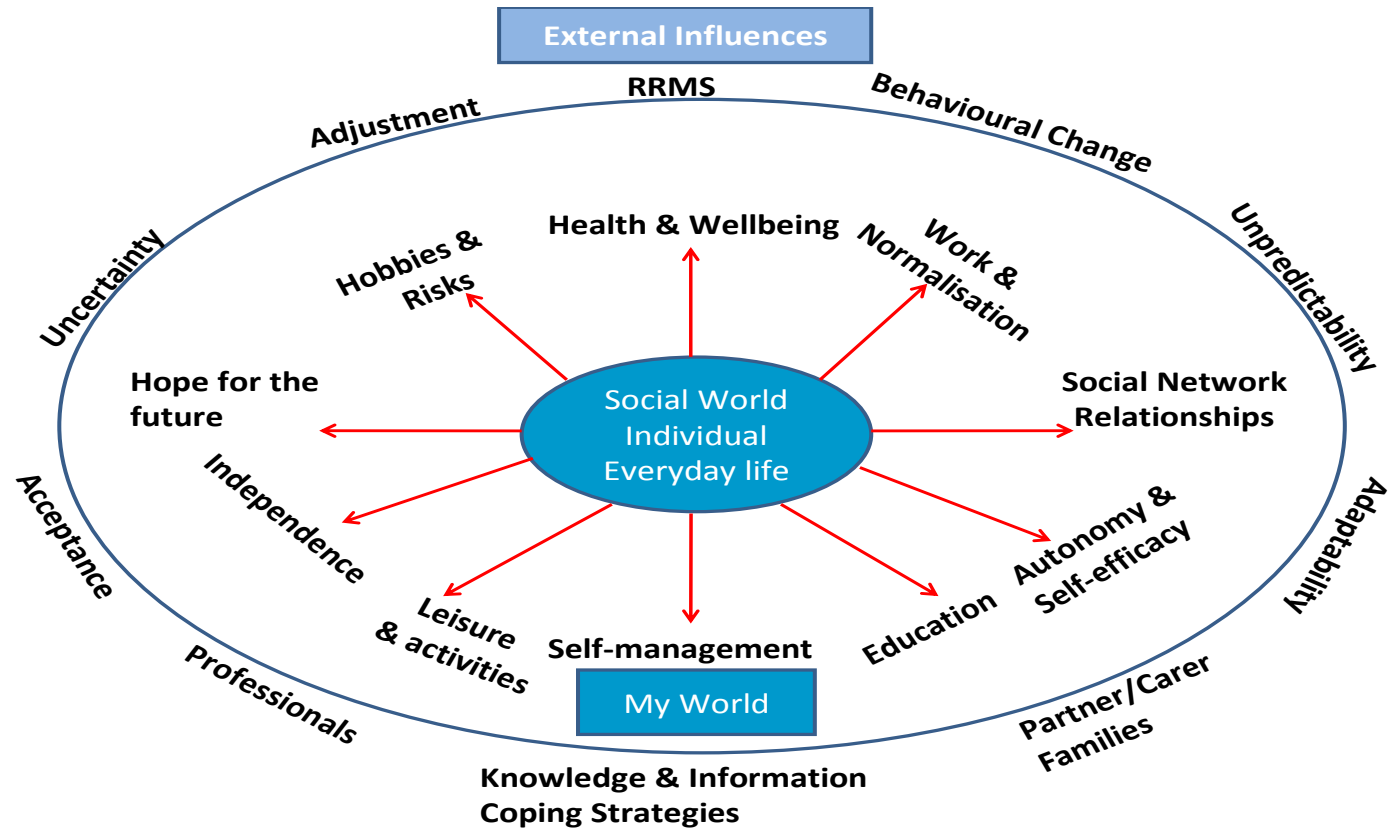
implementing and evaluating of services through the Expert Patient Programme (EPP), Patient / Public Involvement Forums, and the trials of “individual budgets” where service users control spending are all examples of the Governments’ commitment to LTCs. These all profess to be supporting the individuals and professionals towards engaging with self-management, self-efficacy and better usage of scarce resources. But the differences in conceptualisation are not clear and they are referring very much to the more acute aspects of self-management. This is evidenced through the recommendations and the performance measures which have been set through the Government targets, with focus on reducing acute episodes of care through A&E; outpatient visits and admission to acute care beds. Awareness of the tensions between acute and LTC demonstrates contradictions in social, political and ideological approaches to caring for people with enduring health and social care needs.

UK Health and Social Care Workforce Support and Guidance

The updated General Medical Services contract for general practitioners will reward doctors who deliver high standards of care as measured through the Quality and Outcomes Framework (QOF). The introduction of the role of Community Matrons was planned to support people with complex conditions and also the pharmacy contract rewards scheme for annual reviews of use of medicines as well as other proactive checks which are aimed at people with LTCs. The Government’s commitment to this new agenda for LTCs has stimulated strategic healthcare planners and providers to explore what action is needed to build on existing services for people with LTCs and their families. Whether this commitment and actions are becoming a reality is not yet known, but reviews are being undertaken in changes of approach and adaptation of conditions such as dementia care, diabetes, arthritis and asthma management.

Integrated care systems aim to involve many different professionals working collaboratively in teams to ensure that the right people are in the right place to provide the right type of care at the right time (Norris et al. 2003; Wilson 1997; Singh 2005). Traditional organisational structures and barriers may need to be

Figure 1.1 : Conceptual Framework



Conceptual Framework

overcome to have all professionals working together in partnership to coordinate the continuity of care, delivering services, supporting new ways of working by promoting collaborative practices and providing patient centred integrated care to optimise long term outcomes (Wilson 1997). The integrated care services revolve around the patient both vertically (strategically, managerially and operationally) and horizontally (across organisations and partnership working). To ensure the skills are available to meet the patient's LTCs requirements through appropriate education and training which promotes the increased knowledge to meet patient needs and multidisciplinary/partnership working which is required to transform chronic care (Wilson 1997).

The Department of Health has identified workforce development as a crucial element of LTCs with the NHS "Skills for Health" organisation to help create a skilled and flexible workforce by developing national workforce competency frameworks, increasing skill levels and promoting qualifications and career frameworks (Skills for Health 2008). The NHS has also produced a LTCs workforce resource pack to support workforce planning (NHS National Workforce Projects 2006c). It provides an overview of current developments, along with a range of practical solutions and examples of good practice. Although health and social care staff are encouraged to actively involve people with LTCs in decision-making and personalised care planning support, the service providers for self-management vary, reflecting local initiatives, as there are no national policies or templates of systems to support them (Nolte et al. 2008b). There is a lack of ongoing national evaluation and focus on equitable access to health and social care services with varying local interpretation of policies and too great a focus on short-term quick wins.

Wilson (1997) and Coulter (2002) predict that successful outcomes for people with LTCs require a partnership between engaged, empowered individuals and a proactive responsive and integrated system. Without an increase and promotion of self-management and self-efficacy the resources for LTCs cannot be sustained indefinitely. There are increasing numbers of people who are living with one or more LTCs. One of the aims of self-management is to promote patients' ability to self-manage LTCs, while working in partnership with the support of services provided by the NHS (Kennedy & Rogers 2001). There are however people who

may not want to be engaged throughout the fluctuating continuum of self-management and some people who may prefer to be a recipient of their care, preferring a paternalistic relationship with, and want to leave the care management to the professionals.

Rationale for this Research Study

Many of the social, political and ideological new initiatives are driving health planning, commissioning and resource management but the emphasis should be on the needs, wants and abilities of the people with different LTCs which should be explored further and given more consideration. Research, such as this project, is required to explore the application of these new initiatives and other sources of literature from the user and professional perspectives. To develop substantive theory going through the LTCs journey through a rigorous and critical exploration of individual experiences. Most of the research that has been undertaken to date on LTCs has focused more on what has been conceptualised as acute conditions, such as asthma, diabetes, hypertension, heart disease where the diagnosis is relatively quick, the person has an interventionist role in managing the condition in order to maintain their own health, lifestyle and well-being. In some cases, such as asthma, self-management can mainly consist of adherence to treatment with the intention of preventing major exacerbations and consequent disruptions to quality of life.

At the other end of the continuum, self-management for LTCs such as rheumatoid arthritis needs not only adherence but also behaviour change and new coping strategies, because symptoms have a great effect on many areas of their life (Newman & Stead 2004). These behaviour and coping strategies are thought to be affected by expectations, increasing individuals' confidence in their ability to perform activities which link the importance of self-efficacy with self-management. The two theories need to work in conjunction through the provision of skills such as problem solving and goal setting to increase self-efficacy and maximise self-management behaviours (see Chapter two). There is a definite gap in knowledge around progressive LTCs such as RRMS and taking the perspectives of people with RRMS, their partner/carer and professionals involved in their care processes.

This research has concentrated on RRMS which is a progressive neurological condition which has a very individual illness trajectory and much uncertainty and unpredictability. There has been less research and reviews undertaken on people with more progressive LTCs which are often harder to, and take longer to diagnose. They are very individual in terms of the different trajectories and prognosis, the roles of partners/carers is crucial throughout the illness experience, with the fluctuating levels of mobility and coping mechanisms. The trajectory in the more progressive LTCs is often initiated with the inevitable grief and loss associated with the diagnosis and the uncertainty of the rate or progression or even stability over time. The research will focus on people with RRMS and follow the MS journey across their illness trajectory from their perspective as well as their partner/carer. The perspectives of the health and social care professionals involved in the care of people with RRMS have also been reviewed. This has allowed an in-depth theoretical analysis of specific components of the one condition and has explicated the emerging understandings about self-management and self-efficacy of people living with RRMS. The research presented in this thesis has made a contribution to the existing body of knowledge through the presentation of rigorously developed theory with the three groups of participants through the development of knowledge and understanding in living with RRMS.

In the past the political, economic, and social trends have influenced the way researchers and clinicians have viewed LTCs and articulated the health care needs of persons with chronic illness (Thorne & Paterson 1998). Longitudinal studies in LTCs are very valuable as many of the studies have been based upon single interview with each research participant (Thorne et al. 2002). This research used a longitudinal study which covered 6 people with RRMS and their partners/carers over an eight month period. This allowed for their storylines to be told with responses to changes such as complications, relapses/exacerbation, financial/social issues and new treatment developments being utilised. The perspectives of the health and social care professionals were also considered and the input that they had into the working in partnership and support of people with RRMS and their partners/carers.

The focus will allow the experiences of the research participants to be expressed and shared, which suggests a qualitative approach, in terms of their individual experiences of living with RRMS. This will identify the distinctive features and attributes of self-management and self-efficacy across their own MS trajectories including the shared experiences of their partners/carers. The ways in which each of the six people with RRMS and their partners/carers reshaped their lives as a result of RRMS were all very different. They were influenced by different factors, life circumstances, individuality and interactions they had with professionals, family members and their own social networks.

An explicit research question and the aims of the study have been formulated from the identified unanswered questions from the literature review and around the conceptual framework using a qualitative paradigm with an open-ended approach. These have been stated below. The research design, methodologies and methods of data collection will be discussed in Chapter three and four; and the data analysis in Chapter five. These findings will be discussed in detail around the MS Journey in Chapters six, seven and eight.

Research Question:

How does engagement with self-management and self-efficacy influence the journey of people with RRMS and their formal and informal carers?

Aims of the study:

- To explore the MS trajectory through the individual journeys of people living and diagnosed with RRMS in terms of self-management and self-efficacy.
- To develop an understanding of the engagement processes and the different levels of involvement which drive the willingness to be involved in self-management and self-efficacy of people with RRMS.
- To increase understanding of the attributes of self-management and self-efficacy from the construct and experiences of professionals, people with RRMS and their partners/carers.

The RRMS Trajectory across the Journey

This research study has explored the concepts of levels of engagement of people with RRMS, their partners/carers and professionals involved in their care. In

building up data and generating substantive theory around the processes of self-management and self-efficacy in order to understand the perceptions, experiences, actions and levels of involvement in self-care. The RRMS trajectory framework begins pre-diagnosis with feeling unwell and uncertain about what is wrong with them, up to the diagnosis of RRMS, which is the beginning of a long journey into the unknown. A journey that may begin in hope, pass through periods of elation and frustration and finally end in levels of acceptance and resignation. The telling of the diagnosis and the explanation of progressive diseases and their treatments form a map which provides a route for the pathway of care (Wilson 1997). This is based on my research and development on Integrated Care Management which provided an evidence-base for focusing on continuity of care, by examining the organisation and management of patient centred care and breaking down professional barriers to allow a smooth transition of required care and better care outcomes. People begin the journey with different knowledge and different ways of receiving and accepting the diagnosis of RRMS.

When people are diagnosed with RRMS it is suggested that they go through a transition and make a series of adjustments to their lives over time across their uneven illness trajectory. The emerging understandings of the experience of the MS transition are important in promoting self-management and self-efficacy for this group of people (Kralik 2002). According to Embrey (2006) the reactions to being diagnosed can be unpredictable and may depend on the individual's coping strategies, and can be influenced by their personality, life experiences, values, beliefs, self-image, self-esteem, internal locus of control, perceptions of self-care and motivation. People need to manage the uncertainty and unpredictability to be able to self-care and have the motivation to be in control. All these factors may promote or hinder a person's want, ability or willingness for ongoing engagement in self-management and the ways, in which they are assessed, acknowledged and managed, as part of the individual's care management. These have been explored further in the contribution of new knowledge and generation of theory and concepts in this research. For a summary of the research study see Figure 9.7.

Chapter one summary

In the first chapter I have provided a brief overview of what lies ahead for the reader in terms of what the researcher wants to know around the research topics.

In the pages to follow are the intimate, personal accounts of the people with RRMS and their formal and informal carers. Their experiences are real, challenging, emotive, positive, but filled with frustration at times, however they continue to play an important part of lives they continue to live. The research pathway will take you through their journeys and sharing their personal accounts throughout this thesis.

Presentation of the thesis through the outline of the chapters.

The thesis is presented in nine inter-related chapters that discuss the literature, methodologies and methods, findings and implications for practice and full engagement with the associated theory. An outline of the content of the proceeding chapters will provide an overview of how the research journey unfolds.

Chapter two – Theoretical Perspectives

The vast literature on LTCs was explored in order to establish a connection between this research and the existing knowledge on the LTC of RRMS. This was undertaken to establish what had been done which identified a requirement for this research in a new area of unanswered questions and helped in generating the research question, design, methodologies and aims of this project. Further exploration of the relevant literature on LTCs was undertaken in terms of engagement with the philosophy of enabling and promoting self-management and self-efficacy. The review presents an analysis of the literature on what is known in the topic areas and the governing policy developments. Theoretical perspectives are drawn from a wide range of sources from psychology through medicine, and rehabilitation to chronic disease management.

Chapter three - Theoretical Framework

The rationale for the adoption of a qualitative paradigm that draws upon the reality tenets in order to develop the theoretical framework for this research study is discussed. It also places the research into its philosophical, theoretical and ethical context within an interpretive framework using social constructionism, interpretivism, symbolic interactionism and grounded theory as ways of collecting the knowledge. Also to help address the issues of social processes, social life patterns, social identities and shared experiences of the participants. It highlights the main ethical considerations relating to the conduct of the research including

confidentiality and anonymity of the participants. The issues of theoretical sampling and theoretical sensitivity and co-construction of knowledge are considered including the sample selection, participant recruitment and the actual participants involved in this research study. Finally the role of the researcher is discussed in demonstrating integrity; trustworthiness and rigour of this research including the use of a reflective decision trail which was the key endeavour of the thesis. Reflexivity makes the researcher self-conscious about what she is doing in utilising the model of knowledge, to grasp where the knowledge comes from through professional learning.

Chapter four – Methods used

This chapter focuses on the research design approach to develop new concepts and new theory for the research study. This includes the qualitative methods of data collection used in this study, namely a focus group, semi-structured interviews, longitudinal studies, self-efficacy questionnaire, personal and reflective diary which will be discussed. The development and implementation of each method is outlined in relation to the completeness and confirmation it conferred to the study as a whole. These methods were decided based upon the unique combination of methodologies and the research question which were formulated to allow data collection without any assumptions being made. Throughout the discussion consideration is given to the various steps taken to ensure, as far as possible, that the research was rigorous in conduct through systematic and transparent data collection by the most appropriate means.

Chapter five - Data analysis

The purpose of this chapter is seeking understanding and interpretation of the data through inducing theoretically based generalisations from qualitative data. This chapter will explain the way that the data analysis was undertaken using multiple methodologies for the central theme and the major themes to emerge to provide the theory generation. Grounded theory informed the process of constant comparison of the data, from which the themes and categories were generated and tested against subsequent data, assisted by using memos and diagramming. Scientific rigour is also considered with the continual focus on the requirement to demonstrate this throughout all stages of the research.

Chapter six - Challenge

Losing control, slow acceptance, uncertainty and accommodation of RRMS is presented and described by the research participants as the roller coaster ride through the turbulent passage of reality. This chapter presents the dimensions of the experienced challenge of self-identity and living through denial/disavowal of starting the MS trajectory with the turbulence at various phases through the MS journey. The unpredictability and loss of control are major factors in trying to understand why they felt unwell with fluctuating, bizarre symptoms which interfered with their functioning and made them feel the need to take action and find out more. The partners/carers were also expressing concern at this time and were also baffled by what was happening and trying to explain the symptoms. The engagement process with the professionals at this time is high in terms of trying to find out what is wrong and to seek meanings for the disruptions to life. The chapter begins by learning about these experiences, about what it was like to receive the diagnosis and coping with the reactions, adjustments and adaptation to RRMS. Evidence for the themes is presented through using quotes taken from the discussions as part of the audit trail.

Chapter seven - Transition

RRMS and other LTCs are illnesses where the lives of people suffering from them and their families are irreversibly changed. They are often viewed as being negative experiences where people requiring continuous and complicated management by the multidisciplinary care teams. In this research study the contribution to knowledge focused much more about the positive aspects of RRMS and how these people made the most of their lives and reconstructed their lives with RRMS. They continually stated that they had RRMS, but that it did not have them, and that they had to make the most of their lives.

Being engaged in the story telling process seemed to provide all participants with a sense of self-worth and personal power. It seemed to stimulate reflection and gave them the chance to think about their own situations, and working out what really mattered to them. Many of them stated that they had not spoken to anybody in such depth before and that they had stated things that were in their minds but had never been verbalised before. They welcomed the opportunity for me to share their RRMS journey with them as we went through the roller coaster ride together

with the turbulence of social reality. They were also happy for their partners/carers to be involved as they felt they also needed time to share their own experiences and that generally they only discussed the medical and physical aspects of their illness together.

Chapter eight - Transformation

This chapter describes the transformational phase of the MS trajectory which was the stage when the people with RRMS and their partners/carers started to cope with the intrusion of MS. By getting their lives back in control through adjustment, coping and enhanced quality and meaning of life. The relationships between the people with RRMS, their partners/carers and the professionals were changing through independence, mastery and self-determination. The research participants described this phase as taking on a new philosophy of life through personal growth, embracing MS and making the best of their lives. With discussions around how they put their lives back together again, looked at their health within the illness and starting to look more to their visions for the future.

Chapter nine - Discussions and conclusions

The final chapter selected and reviewed five theoretical concepts and applied them to the themes which were developed. Through seeking understanding and interpretation in making sense of what has been learned through the research process. The theory and theoretical models present an overview of the research and the contributions made to knowledge and understanding and implications for practice and policy. Suggestions are also made for further research within this field of study, and utilisation of self-management behaviours to break down barriers through increased recognition of engaging with self-efficacy and enhanced coping mechanisms.

Chapter Two – Theoretical Perspectives

Introduction

Chapter one set the scene for the research by describing the context in which the research was conducted. This explored the background events and experiences that led to inquiring about the engagement of people with RRMS, their partners/carers and professionals involved in their care, in terms of self-management and self-efficacy. LTCs are the foremost health problem globally. Health and social care professionals are presented with both a challenge and an opportunity to offer integrated care. This ensures that people with LTCs have a collaborative journey. The purposed of this chapter is to establish the connections between this research study and the existing knowledge on the LTC of RRMS to justify the research topic, research design, methodologies and the development of the research question based on what the researcher wants to know. The review presents an historical analysis of the literature on what is known in the topic areas and the governing policy developments which will be evaluated in relation to the research which is being proposed.

Theoretical Perspectives

The review provides an overview of the current knowledge within the literature from a wide variety of sources and disciplines. This chapter will frame the proposed research within the relevant literature of LTCs and to explore the current state of knowledge of the key theories, concepts and ideas which will assist in the development of the research question. It will draw upon the philosophy of enabling and promoting self-management and independence through enhancing the self-efficacy of people with RRMS. A vast body of literature, authored within a variety of disciplines, has developed over the last three decades with a focus on LTCs. Much of this is disease focused and grounded in the empirical paradigm, which is based on observation or experiences. The LTC literature is so extensive in fact, that it is impossible and in this case not necessary to review the entire body of knowledge as it is beyond the remit of this research study which is focused on the main questions and problems that have been addressed to date. For this reason, the purpose here has been to review the literature through the theory of knowledge, design, practice and evidence; that has focused on questions around the dimensions, influences and understanding the experiences of the impact of

engagement with self-management and self-efficacy across the MS Journey (See Figure 2.1). The three sections outlined will each be concluded through summaries at various points appropriate to the topic areas.

Background of Long Term Conditions

There are several drivers from political, economic, professional and user groups influencing and driving self-management and self-efficacy yet they are still not totally understood, hence the need for this research. The purpose of the proposed research is through an interpretive knowledge approach to create new knowledge through constructed processes, from people with RRMS, their partners and carers and professionals involved in their care, through their experiences and perspectives in engaging with self-management and self-efficacy.

The increase in the prevalence of LTCs represents a growing challenge to healthcare systems worldwide and LTCs have been stated to account for more than half of the global disease burden being described as a primary challenge for the 21st century healthcare systems (Lau-Walker 2009). The World Health Organisation (WHO) predicts that LTCs will become the main worldwide cause of death and disability by the year 2020 (Epping-Jordan 2001). The Department of Health have estimated that 70-80% of people living with LTCs could reduce the illness burden and costs by appropriate self-management practices because of the associated decreases in hospital admissions, disease progression and the development of other conditions (DH 2004b). It is clearly recognised that in order to reduce risks and improve outcomes LTCs support must be shared with patients and their families through more joint working. Yet there seems to be little stated regarding multidisciplinary collaborative working through integrated care processes which are patient centred and based on individual needs and outcomes. This identifies one of the gaps in knowledge centring round the actual policy, practice, and reality identified which needs to be addressed and will be contributed to within this research. The research will focus on RRMS as a progressive neurological condition in which there has been limited research of the concepts of self-management and self-efficacy.

Figure 2.1: Subject tree on the literature review of Engagement with Self-management and Self-efficacy across the MS Journey.

Section One: What are the dimensions and impact of engagement with Self-Management (S-M) and Self-Efficacy (S-E)?

Historical/current interpretations Definitions/Complexities Theories/Concepts Epistemologies Research Question

Section Two: How can experiences of engagement with S-M and S-E be understood?

Self-Care Engagement in Care Empowerment Autonomy S-M and S-E Behaviours

Section Three: What influences engagement with S-M and S-E according to the Literature?

Governing Developments Political Standpoints Paradigms/Care Models Health and Illness Partners/Carer and Families

MS Prevalence and Incidence

MS is the most common neurological disease in young adults. It is a progressive, disabling disorder that affects the brain, nerves and spinal cord. It affects up to 2.5 million people worldwide, with an estimated 100,000 in the UK. Between three and seven people per 100,000 population are diagnosed with MS each year and about 100 to 120 people per 100,000 population have MS. To date little is known about its aetiology. Genetics, lifestyle, local environmental factors and obsessive behaviours are thought to have an impact on MS (MS Society 2008). There has also been an association with a history of viral infections during early life and the development of MS later on (Ghadirian et al, 2001).

MS is characterised by patchy inflammation, gliosis (forming scars) and demyelination within the central nervous system (CNS). This results in damage to both the myelin sheath (a layer of fatty protein that protects the nerves in the same way that insulating material protects an electric wire), which protects and insulates the neural axons in the CNS, and to the oligodendrocytes which serve to maintain the myelin. This damage (called demyelination) disrupts the way in which messages, or nerve impulses, are carried to and from the brain, and so it can interfere with a range of the body's functions. The precise cause of this damage remains unclear; however it seems likely that this results from some auto-immune response.

The term 'multiple sclerosis' comes from 'sclerosis', which means scarring and 'multiple', which relates to the sites of the scarring or 'plaques', which can occur in different places throughout the brain and spinal cord. Symptoms depend on the position and extent of the scarring within the CNS, and on how much damage has occurred. Whenever this occurs the neuronal transmission becomes less efficient or impaired and signals may become slower and/or transmitted in an altered fashion. The nerve impulses supplying information to the brain and instructions to the muscles can become unreliable, or stop unpredictably. Once this inflammation has reduced the CNS often recovers and remyelination can occur. However, sometimes, depending upon the extent of the inflammation, recovery cannot fully take place and a scar, known as a 'plaque' or 'lesion' is left. Over a period of time, increasing amounts of myelin is lost, and in severe cases the nerve fibres within can be irreversibly damaged. The aetiology of MS is unclear but is

associated with an abnormal immune response within the CNS. MS has a latitudinal discrepancy and occurs more frequently in temperate regions away from the equator.

Individuals with MS experience an array of symptoms and disabilities, which can place a major burden on those with MS and their families, as well as on health and social care services and the voluntary sector. Women are almost twice as likely as men to develop MS and in more rare cases it affects children. MS stays with the person for life, causation is not known and no cure has yet been identified. Of the 100,000 people with MS in the UK, about 85% are first diagnosed with RRMS. This means they experience a relapse or flare up of symptoms (also known as an attack or exacerbation) followed by remission (a period of recovery). The effects of MS are wide-ranging, having an impact on physical (reduced mobility, daily living, symptom management including weakness, fatigue and spasticity), psychological (cognitive decline and depression) and social well-being (changes in roles, isolation, stigma, relationships, employment, financial, social fulfilment). People with MS are not a homogeneous population and their needs vary according to their individual experiences of the disease and its symptoms. This research study aims to improve the reader's understanding of perceptions, feelings, control strategies and attitudes of people with RRMS and their partner/carer. This will help to interpret the meaning and intent of differing degrees of engagement with self-management across the RRMS trajectory.

Problems faced by people with MS, may include not only physical impairments, but also restrictions in daily activities, a negative body perception, decreased self-sufficiency, work restrictions and social stigma. The onset of MS can represent an assault on the person's physical self and sense of identity and their self-esteem. One may consider the onset of MS as a personal crisis and Charmaz (1983) even speaks of a "loss of self" due to suffering and having a lack of valued life. Many people with MS put much emphasis on their struggle with bodily dysfunctions. Present management of RRMS comprises of three main elements: the use of disease modifying therapies (DMTs), relapse management and symptom management.

Most current research in MS focuses on understanding its pathophysiology within the biomedical model and the development of new treatments targeted at modifying the effects of the disease and symptom management, while a cure remains elusive. Studies in the UK investigating the perceptions of people with MS and carers are particularly rare. The MS services in the UK are currently emphasised by DMTs and medical care. The way professionals contribute to this care is critical, and the adoption of an integrated model incorporating medical, nursing, rehabilitative and palliative care is required to make an integrated journey for the people with MS and their partners/carers. It has been acknowledged that the priorities of the person with MS may well be different to those of the professionals, and that such factors may substantially influence the outcome of professional strategies.

The Literature Review

In order to critique and undertake an appraisal of existing knowledge the literature to be further reviewed was located following manual library and computer searches involving CINAHL, MedLine, Web of Knowledge, PsycINFO and AMED. There were thirty-five quantitative studies and one hundred and thirty-eight qualitative studies identified on LTCs experience, “using the search terms of self-management, self-care, self-efficacy, self-esteem, LTCs, MS, engagement, education, cognitive, empowerment, self-advocacy, competence and control, chronic illness, chronic disease”. As an open-ended interpretative approach was deemed to be necessary to socially construct knowledge, and allow data collection without assumptions being made, further analysis was undertaken on the qualitative studies.

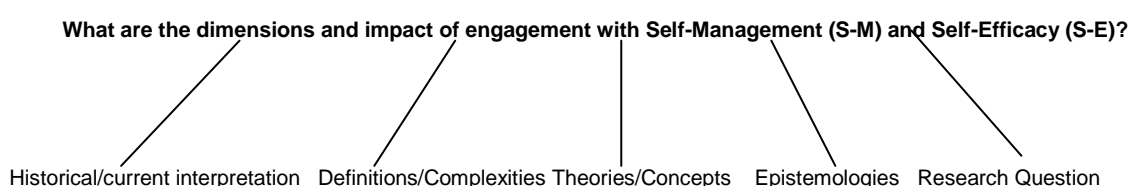
Those qualitative studies published between 1980 and 1999 focused on concepts such as suffering, self, disruption and loss (Bury 1982; Charmaz 1983, 1987, 1999; Kleinman 1988; Miller 1997). The years between 2000 and 2009 identified one-hundred and eight qualitative research papers published which focused on illness experience. Within these research papers there were twenty-four qualitative studies identified for self management and self-efficacy of diabetes (Anderson et al. 1995, 2000; Feste 1992; Glasgow et al. 2000; Hernandez 1995, 1996; Melville et al. 2000; Paterson et al. 1994, 1998, 1999; Pooley et a. 2001; Thorne et al. 2001); eight for asthma Cabana et al. 2000; Gibson et al. 2002); four for

hypertension (Brown et al. 2007; Nakagawa-Kogan et al. 1988; Naik et al. 2008) and two for heart disease (Clark & Dunbar 2003; Richards & Emslie 2000). There were no studies identified on the databases which explored the effects of engagement on self-management and self-efficacy of people with RRMS. The key messages from these studies will be transferred and built upon in their applicability to progressive neurological conditions such as RRMS.

It became apparent that the studies of qualitative researchers have shifted over the past three decades from an 'illness as a burden' focus by outsider perspectives (with no personal experience of living with the illness) to an insider's perspective of living with LTCs which has revealed images of health and adjusting daily lives and life plans within illness (Thorne & Paterson 2000). An insider's perspective of LTCs reveals a distinct knowledge from the perspective of the person living, adjusting and coping with their LTCs. The more recent literature reveals a growing acknowledgement of the expertise of the person living with the LTC. The literature review revealed the main questions and problems with LTCs including RRMS that have been addressed to date. Figure 2.1 maps out the topic structure and how the knowledge within this review has been organised to cover the origins and definitions of the research areas. The literature review will identify what has been undertaken to date and what the unanswered questions are, which will highlight concepts and theories for this research to address, and the formulation of the research question.

Section one will review the dimensions of self-management and self-efficacy including the historical context as well as the current interpretations and understanding of these concepts.

Section One: Dimensions and impact of engagement with self-management and self-efficacy.



Historical context and current interpretations

Self-management is not new challenge in the field of health and social care but has been discussed from at least the seventeenth century onwards. Yet the increasing burden of LTCs is driving this approach to reduce pressures on healthcare systems and to address the needs of people with chronic incurable illnesses. With numerous publications attesting the growing market to meet the needs of self-help (Hurwitz 2006) yet the impact on patient engagement in self-management remains low. According to Holman (2005) there has been an emerging illness burden developing over the past half-century with heavy reliance on medical support, whilst Newbould et al (2006) stated that models of coping with adversity which are based upon the virtues of self-help, self-reliance and family and community resilience were common in Victorian Britain. They all argue that many of today's practitioners and patients have long promoted self-management and self-efficacy over the last century with mixed responses. Yet we still have them as misunderstood and ill-defined concepts today, to which many people attributed to their own interpretations, which causes further confusion and uncertainty. This research will structure these concepts into a coherent framework to enhance understanding and interpretation.

Self-efficacy is believed by Lorig et al. (2001) to have a major impact on self-management in terms of self-confidence and self-control in the individual's ability over their own capabilities and actions. The concept of self-efficacy from Bandura's Social Cognitive Theory (1989) states that it is an individual's belief that they have the ability to overcome challenges presented to them. It is one's own perception of efficacy which proves significant, rather than the actual reality of their ability to overcome the challenge faced. It incorporates concepts such as mastery, verbal persuasion, self-esteem and self-control in present and future events.

According to Bandura (1977; 1982) having self-efficacy about one's ability to perform skills and deal with challenging situations is a strong predictor of one's subsequent performance. It has been shown to predict health related behaviour changes in a number of LTCs through perceived control and confidence in executing an action (Bolton & Brookings 1998). The Expert Patient Programme (EPP) was set up within a framework of self-efficacy aiming to increase levels of

perceived self-control, confidence and self-management. A recent longitudinal randomised control trial (Barlow et al 2007) in line with similar studies (Kennedy et al. 2007; Griffiths et al. 2005; Barlow et al. 2000) showed small, but nonetheless important, effects on self-efficacy and depression with trends towards improvement of outcomes. People with MS found the EPP too basic and felt it could focus more on issues such as fatigue management, employment and acknowledgement of their existing self-management skills. This could be due to their needs being more intricate than other people with LTCs who are targeted by the EPP. However, Barlow et al. (2009) stated that the EPP may be of more benefit to people with MS who were experiencing mild to moderate levels of anxiety and depression.

Previously, according to Wassem (1992), for individuals with MS, self-efficacy judgements regarding self-management and psychosocial activities were related to adaptation and adjustment. Barnwell & Kavanagh (1997) also found that self-efficacy has a predictive role regarding social activity and control of negative thoughts in individuals with RRMS. However they found past performance to be the most significant overall predictor. Low self-efficacy appears to be related to a high incidence of depression in RRMS (Shnek et al.1995), and in low self-esteem for the general population.

These outcomes may be in line with this research study where none of the participants had attended an Expert Patient Programme (EPP). The initial design of the study was to try and compare engagement with self-management between those who had attended the EPP and those who had not and the impact this may have had on their self-efficacy. However, despite not attending the EPP many of the people with RRMS, according to the literature, seek to control and manage their own approaches to living with their illness through their own coping strategies. There are a wide range of epistemological and philosophical backgrounds of medicine, psychology, nursing, public health, economics and anthropology which have contributed to the current concepts of self-management and self-efficacy. These have resulted in fragmented information derived from differing and often opposing theoretical perspectives and frameworks which have resulted in a wide range of definitions making them complex concepts, which are poorly understood

and applied. Section one will review these concepts in terms of defining and applying them to this research study.

Definitions and Complexities of Self-management and Self-efficacy

There are confusions between the different terminologies used and the actual definitions which are often used interchangeably. The aim is to explain these terms and the support interventions suggested for people with RRMS throughout the literature reviewed.

Defining Self-management

Self-management is a complex, ill-defined concept which has caused confusion and misunderstanding among professionals, the general public and people with RRMS. The Government's agenda and policies are driving self-management in promoting patients' ability to work in partnership with NHS support service through the care philosophy of increasing patient power and responsibility to ensure healthcare actions are taken. These building blocks of the governing developments will be addressed later in this chapter. There is no clear definition of self-management. One of the most referred to definitions in the literature is:

"Self-management refers to the individual's ability to manage the symptoms, treatment, physical and psychosocial consequences and life-style changes inherent in living with a chronic condition. Efficacious self-management encompasses ability to monitor one's condition and to affect the cognitive, behavioural, and emotional responses necessary to maintain a satisfactory quality of life. Thus, a dynamic and continuous process of self-regulation is established". Barlow, Wright, Sheasby, Turner & Hainsworth, (2002) p. 178.

This definition highlights that self-management is complicated for people with LTCs requiring individuals to make a number of changes to their coping mechanisms in order to live with their condition as well as look after themselves and their lifestyle in general. It implies that self-management is more than adherence to clinical guidelines or medical regimes because it also incorporates the psychological and social management of living with a LTC. This also fits in with the biopsychosocial paradigm model which will be discussed under the different models and applications of care delivery later in this chapter.

The dominant philosophical value of self-management interventions which train people to utilise relevant skills to help themselves was first mentioned in the Saving Lives: Our Healthier Nation White Paper (DH July 1999). It proposed that

self-management may be one means of bridging the gap between patients' needs and the capacity of health and social care services to meet those needs. Barlow et al. (2000) also suggested that self-management approaches which are continuous and dynamic produce better outcomes than other more traditional approaches.

Anderson et al. (2000) see self-management as the daily activities that people in general with LTCs use to promote their health, manage symptoms and decrease the effect of their LTCs on their functionality and psychosocial effects. Whereas others see self-management more as an active responsible and flexible process that will result in personal development (Corner 2001, Ricka et al, 2002). Lorig & Holman (2003) proposed that satisfactory self-management requires the basic skills of problem-solving, resource utilisation, and the forming of an individual professional partnership. However it has to be recognised that not all people may want to or are able to be fully involved in self-management and some people may prefer to be a recipient of care, preferring a more passive or paternalistic relationship. Some people want to leave the care management to the professionals and or have dependency on others to support them with their LTCs. The reasons for this are diverse but factors such as age, gender, level of education and social class have been noted as influential factors (Corben & Rosen 2005). The people who make these personal choices are within their rights to do so. Within the healthcare system models, there has to be a potential continuum of relationships which are not static, but can be re-negotiated over time, as knowledge, skills, abilities and confidence may change individual choices.

Glasgow et al. (2003) discussed self-management as the activities usually undertaken by the patient between planned contacts with healthcare practitioners and services. These activities involve managing symptoms, treating the condition, coping with the physical and psychological consequences inherent in living with a chronic condition and making lifestyle changes. Here the self-management focus is on the activities that individuals who are able to can undertake for themselves and it implies that it includes the activities that people undertake to create order, discipline and control in their lives and lifestyle.

As highlighted self-management is a complex and multifactoral process which has substantial effects on the patient, their family and the professionals involved in

their care. Supportive networks and collaborating with other people with MS is also important for people to learn from each other and share their experiences and achievements. Lorig & Homan (1993) state the aim of self-management is to minimise the impact of chronic diseases on physical health status and functioning, and to enable people to cope with the psychological effects of the illness. They also support the suggestion of self-management as a collaborative activity between patient and professionals. They suggest that by enabling people to minimise pain, shared decision-making about treatments helps people to gain a sense of control over their lives. There is no mention of the support or sharing of experiences and constructed meanings from their formal and informal carers.

Self-management has multiple meanings with the dominant model being medical self-management and the literature assuming that self-management means the same to professionals and people with LTCs (Koch et al. 2004). Much of the literature has been written from the perspectives of health professionals with the assumptions that professionally driven education will provide sufficient actions for people with LTCs to self-manage. Such as with self-management being reported as teaching and enabling people to minimise pain, share decision-making in their treatment, gain a sense of control over their lives (Lorig & Holman 1993; Barlow et al. 1999), reduce the frequency of visits to medical doctors and enjoy a better quality of life (Lorig et al. 1998; Barlow et al. 2000).

More recent research has been undertaken through the involvement of people with LTCs providing the insider's perspective of living, adjusting, communicating and coping with support. A review of the key exemplar research papers will highlight what is known within some of these explored meanings, dimensions and experiences of self-management.

Theories and concepts of engaging with Self-management

Kralik et al (2003) discussed self-management as taking action to create order to incorporate the consequences of illness into the lives of 9 people with arthritis. The concepts explored were around active learning, exploring the illness boundaries, balancing, pacing and prioritising the order of life and using resources. They concluded that self-management was a process of involving the physical and psychological responses to LTCs through constantly planning, pacing and

managing life as a means of creating order. The 9 people involved shared their experiences by writing their autobiographies about living with their illness and formed the notion of understanding the meaning of self-management. This study involved two telephone interviews one as an introduction including the purpose of the research; and the second as a semi-structured interview and discussion dinner meeting of all participants and their partners with the researchers. These provided a snapshot in time over three episodes with the research participants writing or recording their own experiences which were fed back and validated during the group meeting.

Similar to the above research, Koch et al. (2004) undertook participatory action research from the standpoint of 24 older people with asthma in which they explored the self in self-management through story telling. The key concepts explored were control, shared decision-making and management of self, self-determination and experts in their own condition. Koch's research stated that they felt the self had been ignored in favour of the person with asthma being objectified as the 'patient'. Their argument was on the need to focus on providing people with the means to grow and learn in participative relationships which cannot be realised with "off the shelf" self-management solutions. They stated that patient compliance through adherence to treatments was not self-management. The research participants expressed the importance of having order in their lives and taking control to manage their own self. Data was generated over nine months from one in-depth interview, an open ended questionnaire and action research groups (equalling eight hours of contact time). This research brought clearer definitions for people with asthma in terms of being experts in their condition and being more involved in the care process.

Research was undertaken by Thorne et al. (2004), through their interpretive descriptive study of communication issues within the diagnostic phase of MS, from the standpoint of 12 participants who were at least 5 years post-diagnosis. The key concepts were communication, illness experiences, disease management, uncertainties and ambiguities, conflict and adjustments. Thorne concluded that MS as a complex progressive condition with changing life circumstances requires self-management and increasing self-efficacy to look after oneself properly and to live a normal life.

They used in-depth interviews and focus groups to explore interactions with the health care system. They discussed fragmented healthcare and conflicts over diagnosis, explanations and treatment around communications; with professionals being described as a source of comfort and strength or frustration and anger through professionals being supportive and empowering or accentuating feelings of being isolated. People with MS expressed the importance of being respected as competent and knowledgeable through being a partner in healthcare decision-making. The data was collected from one interview and was synthesized into themes for clarification and refinement through the focus groups. Again the focus was on involvement in the care process through important information sharing and decision-making. There was no role identified for partners/carers being involved in a supportive process.

These three key research studies have all taken different methodological approaches to facilitate the collection and analysis of data to explore dimensions of experiences and support for self-management of people with LTCs and all with intellectual worth. However, they have provided more of a snap-shot in time with limited involvement of the research participants and have focused only on the people with LTCs. This creates a gap in knowledge for a longitudinal research design to explore experiences and perceptions over time with people with LTCs which could be expanded to include their formal and informal carers.

The key concepts used in these three studies included active learning, exploring the illness boundaries, balancing, pacing and prioritising the order of life, using resources, control, shared decision-making, management of self, self-determination, experts in their own condition, communication, illness experiences, disease management, uncertainties and ambiguities, conflict and adjustments. Through synthesizing the concepts used in these research papers around constructing meaning of self-management different philosophical approaches could be utilised to obtain more in-depth information from selecting different groups of research participants to generate new knowledge and theory. The conceptual framework in Figure 1.1 was drawn up to expand on the concepts from the literature review and to explore areas where a contribution to knowledge could be made through utilising major central concepts within the proposed research topics. Given the unpredictable trajectory of MS and its challenges,

health and social care policy makers and professionals need to understand the journey of people with MS and what self-management means to them. There is a knowledge gap in the effects of the unpredictable and uncertainty of RRMS and the consequences of being engaged with self-management. The aims of the proposed research study will be formulated to fill these gaps in knowledge and will assist in addressing and refining the research question.

Epistemologies in the impact of engagement with self-management

The methodologies chosen for this research study based on the literature review; are through a qualitative paradigm of interpretivism with social constructionism and symbolic interactionism utilising Grounded Theory. Interpretivism will address the ways the research participants understand the social and cultural life across the MS journey. Social constructionism will allow people with RRMS to construct and reflect on their understandings of their experiences in the diverse situations in which they have them. Their partners/carers and professional carers often support these constructions and use them to work through the challenges and contradictions with them. Symbolic interactionism assumes that these actions depend on the meanings that people ascribe to their situations and the shared assumptions and languages that they use, looking at self and meaning as processes. Grounded theory will be used to study RRMS longitudinally to develop different phases through further developing conceptual categories and generating theory.

From a review of the literature there was the identification of what was known in the subject area and identification of gaps in the knowledge base this led the researcher to identify a research question. There have been multiple revisions of the research question due to the epistemological developments as the research progressed that merely lent more focus to the research process. This highlighted the need for the researcher to consider the nature of the research problem through the literature review prior to selecting the most appropriate research approach and, subsequently, the methods.

Research Question:

How does engagement with self-management and self-efficacy influence the journey of people with RRMS and their formal and informal carers?

Through the addressing and refining of the research question the literature review addressed the dimensions and impact of engagement with self-management and self-efficacy. First, in addressing the research question there was a review of the epidemiology of LTCs including RRMS and information which were important to understanding the drivers and influences of self-management and self-efficacy in the literature. This led to understanding the concept of engagement in self-management, next the review will move on to finally addressing how to go about finding new information and deciding how the experiences can be understood within this research. The literature review helped in the development of the research concepts, the research approach, methodologies and methods to use in order to explore the research question with the research participants.

Defining Self-efficacy

Self-efficacy refers to an individual's belief in their capacity to successfully learn and perform a specific behaviour (Bandura 1989). A strong sense of self-efficacy leads to a feeling of control and willingness to take on and persist with new and difficult tasks. People with RRMS can be empowered and motivated to manage their health problems, if they feel they want or need to. Developing self-efficacy in their abilities, knowledge and skills can lead them to set personal goals and develop effective strategies for achieving them. Morris et al. (2008) state that self-efficacy has its strongest effects on behaviour under challenging circumstances. This could impact on people with RRMS in terms of uncertainty and unpredictability. Engagement in self-management and self-efficacy requires successful support strategies which are tailored to individual needs and behaviours which could be targeted towards the people with MS who have the greatest difficulty in taking care of their health. Efficacy expectations are beliefs in one's capabilities to organise and execute courses of actions to produce outcomes (Bandura 1998). The action is in the behaviour itself and not with the outcomes or events that led up to it. The general themes which have been reviewed through this research are:

- the relationships and partnerships between people with RRMS, their partners/carers and professionals
- the type of accessible information, support, encouragement and signposting
- the flexibility of integrated care services provision to fit in with people with RRMS, their symptoms/disabilities and their other commitments.

People with RRMS may benefit, if they want to become engaged in them, from interventions designed to improve the capacity for self-management, through improving knowledge and building self-confidence. Beliefs in self-efficacy promote personal change through motivation and action. The active involvement of people with RRMS, who want to be involved in decision-making and collaborative relationships with professionals, may encourage ownership of their own health and social care. Encouraging patients to express their preferences and improving opportunities for shared decision-making could lead the transition to greater self-management.

One important aspect of living successfully with RRMS is perceived self-efficacy. Bandura (1986) defines self-efficacy as an individual's judgment of his or her ability to organise and implement a course of action necessary to accomplish a task. According to Bandura (2002), beliefs about one's capabilities and aspirations are influenced by one's family, the educational system, mass media, and culture at large. Fraser & Polito (2007) state that men and women with MS could benefit from strategies to enhance self-efficacy. In chronic illness, one's sense of self-efficacy can be enhanced through modelling of self-management skills, guided mastery experiences, and informative feedback (Bandura 1997). Promotion of self-management could be useful to maximise the person's functional level and quality of life. According to Ennis et al. (2003), self-efficacy beliefs develop from cognitive appraisal of information arising from four types of experience:

- **performance, vicarious experiences** where learning occurs through observation of others, where it is important that the other person or 'model' has similar characteristics
- **verbal persuasion** through influence of others' suggestions, particularly those considered to have a special knowledge of the subject
- **physiological feedback** with feeling better when in more control.
- **achieving mastery** over a difficult task through improved performance increasing levels of self-efficacy.

The acknowledgement that behaviour is fundamental to the promotion and maintenance of health and the idea that psychological status and self-efficacy are

important influences in achieving and predicting self-management (Nodturt et al. 2000). They are therefore essential to further understanding the concept of self-management and self-efficacy which are the core issues of this research proposal. The ethos of self-management closely resembles Bandura's theory (1986) of self-efficacy. In effect, the management of a LTC is characterised by the responsibilities people need to take (Lorig & Holman, 2003). Barlow et al (1998) defined self management as an individual's ability to manage the consequences of the condition, adapting and changing behaviour, making life-style adjustments necessary to living with a LTC. A strong sense of self-efficacy is stated to lead to a feeling of control, and willingness to take on and persist with new and difficult tasks.

However, Kendall & Rogers (2007) state that the theory locates responsibilities for LTCs to the individual. Self-efficacy, self-image and self-worth are all constructs drawn from clinical tradition that have been driven by attempts to account for subjective distress. The 'self' they state within this tradition is one viewed as being deficient or lacking in the properties to be a whole of fully functioning individual. They state this is clearly seen in the original conceptualisation of self-efficacy by Bandura (1994):

"A strong sense of efficacy enhances human accomplishment and personal well being in many ways. People with high assurance in their capabilities approach difficult tasks as challenges to be mastered rather than as threats to be avoided. Such an efficacious outlook fosters intrinsic interest and deep engrossment in activities. They set themselves the challenging goals and maintain strong commitment to them. They heighten and sustain their efforts in the face of failure. They quickly recover their sense of efficacy after failure or setback....." (p. 71).

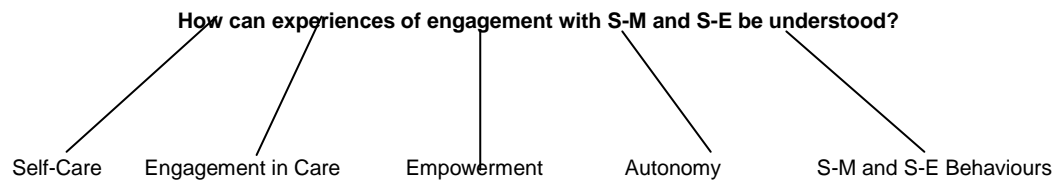
Kendall & Rogers (2007) believe that by adopting self-efficacy as the primary mechanism of success in self-management interventions, models of the costly and "non-compliant" patient may be replaced by a subjective deficient model in which people are viewed as lacking properties needed to be an appropriately functioning and independent. They stress the importance of social disability and illness to the ongoing success of the self-management concept. People with LTCs could be empowered and motivated to manage their health problems (if they choose to be) when they feel confident in their ability to achieve this goal. Consequently, the ability to self-manage has led some researchers to believe that increased levels of perceived self-efficacy might be responsible for positive outcomes in functional disability (Davies et al. 1998).

Summary of Self-management and self-efficacy

The theoretical underpinning for the self-management and self-efficacy of LTCs originate from the psychological and behavioural science literature, based on the notion of an individual's ability to take control of their health and effectively manage their illness (DH 2001, Lorig et al 1999). The important concept in self management is self-efficacy, which is described by Bodenheimer et al. (2002) as having confidence to carry out behaviour necessary to reach a desired goal. This may not be as straightforward as they imply because of the compatibility of desired goals between people with RRMS and their formal and informal carers. Self-efficacy beliefs determine how people feel, think, motivate themselves and behave. It is about people having confidence in their own ability to manage. Self-efficacy can therefore be described as a sub-category of behaviour in the conceptual framework of LTCs management (Lorig et al. 1999). The acknowledgement that behaviour is fundamental to the promotion and maintenance of health and the idea that psychological status and self-efficacy are important influences in achieving and predicting self-management (Nodturt et al. 2000). These are therefore essential in improving the understanding of the concepts of self-management and self-efficacy which are the core issues of this research study.

Most of the research has been undertaken in the areas of diabetes, asthma and arthritis with some more recent studies into coronary artery disease and HIV. Self-management is a growth area for a number of LTCs in many countries around the world. There is an increasing interest in understanding the value of self-management and self-efficacy interventions for people with LTCs. Very little research has been undertaken with people with progressive neurological LTCs. There is a gap in new knowledge and this research involving RRMS will contribute to the knowledge base. People with RRMS may suffer from cognitive impairment, illness uncertainty and unpredictability, functional limitations and mobility problems. Utilisation of self-management and self-efficacy could facilitate coping with and minimising problems and thereby enhance quality of life and well-being.

Section Two: Understanding experiences of engagement with self-management and self-efficacy.



There are certain components of information and knowledge which need to be understood in order to enhance engagement and the utilisation of self-management behaviours to further develop self-efficacy. These include an understanding of self-care and how this differs from self-management; and the concepts of engagement; empowerment, autonomy and self-management behaviours which will be covered in Section two.

Defining Self-care

Self-care is often used interchangeably with self-management and it is important for the terms to be understood and how they relate to each other. One of the very first definitions of self-care came from Levin (1979) which described self-care as a process in which a lay person acts on his or her own behalf in the promotion of health, disease detection, prevention and treatment. This was closely followed by Bolaria (1979, in Segal & Goldstein, 1989) which stated that self-care obscures the extent to which health and illness depend upon socially determined ways of life, obfuscates the social causes of disease, shifts responsibility for health and illness back onto the individual. This definition individualises what they see as essentially a social problem, and promotes a course of action orientated towards changing individual behaviour and lifestyles rather than existing social, economic and political institutions and the health sector. A person's own self-determination may help them to decide whether to take no action but to cope by themselves or whether to consult with a healthcare provider (Dean et al. 1983). The belief is that it is immaterial whether this leads to self-care or contact with professionals, as self-care is not opposed or contrasted with professional care. The suggested definitions here involve self-care through partnership working and involving the professionals when required.

The WHO (1983) defines self-care more holistically in terms of the activities individuals, families, and communities undertake with the intention of enhancing

health, preventing disease, limiting illness and restoring health. Dean (1989) emphasised that LTCs depend on effective self-care for maintenance of function and residual health with input from their partners/carers and professionals in effective listening, encouragement and guidance to help people to help themselves. However, Orem (1991) described self-care as activities that people initiate and perform, within time frames, on their own behalf in the interests of maintaining life, healthful functioning, continuing personal development and well-being. Suggesting control and confidence and links to self-efficacy. May (1997) sees self-care as embodying a philosophy of holism and distinctive life styles which draws together the fragmented experience of health and illness (i.e. psychological, physical and social strands) and which acts to reinforce the wholeness of personal relationships. These definitions reflect that self-care is part of the skills and knowledge of the individual and that they become part of their daily coping with their own personal care and well-being.

Definitions of self-care can be more or less appropriately judged by what use is made of the definition, for example; more recently self-care has been seen as a significant element in managing resource demand (Bodenheimer et al. 2002) and is also regarded as an empowering right for patients (European Parkinson's Disease Association 2003; Salter 2004). The timings of the utilisation of self-care also differs over the illness trajectory where initially there may be no input in the early stages but with the lead up to diagnosis there may be more professional input and then there may be a mixture of self-care with support and interventions from the professionals as and when required. Yet Clark (2003) asserts that self-care does not involve professionals and the individual independently attains and preserves their desired level of health. As most LTCs require input from a team of professionals this makes the term 'self-care' according to Clark, incongruous with management of a chronic diseases. The Department of Health (2005b) uses a similar but slightly more elaborated definition of self-care:

"the actions people take for themselves, their children and their families to stay fit and maintain good physical and mental health; meet social and psychological needs; prevent illness or accidents; care for minor ailments and long-term conditions; and maintain health and well-being after an acute illness or discharge from hospital" p.10.

This definition again puts the emphasis on the individual and their families. Whereas Chambers (2006) suggests that self-care is a continuum which flows from the individual responsibility for lifestyle choices and risks through to self-

management of illness that may or may not involve professionals. At the other end of this continuum is shared care with total reliance on medical care. Therefore shared care involves professionals working together with individuals coping with acute and long-term health conditions, whereas major trauma and compulsory psychiatric care, where the patient is unable to contribute to their care, are examples of pure medical care. However, taking this to another level Wilson et al. (2006) and Redman (2007) contend that the main distinction between self-care and self-management is that tasks that were traditionally performed by professionals are now undertaken by the individual living with LTCs.

In contrast to Segall & Goldstein (1989) who looked at efficacy by highlighting the important issue as being not who provides the self-care, whether it is an individual or professional, but more whether the care is self-managed (i.e. ultimately within the control of the individual). Rijken et al. (2008) states that self-care may include behaviour and actions taken by those who are healthy, at risk of ill health, experiencing uncertain symptoms, diagnosed with an illness or in the process of receiving treatment. They state this could encompass specific types of self-care such as self-diagnosis, self-management, self-medication and self-monitoring.

Self-care could also be understood as people being responsible for their own health and well-being through staying fit and healthy, physically, mentally and where desired, spiritually. This also includes taking action to prevent illness and accidents, the appropriate use of medicines and treatments of minor ailments (DH 2005b). Self-management, then, may be viewed as a subset of self-care. Whereas, self-management and self-efficacy are inextricably linked with an individual's ability, in conjunction with family, community and the appropriate professionals, to successfully manage the symptoms, treatment, physical, psychosocial, cultural and spiritual consequences and inherent lifestyle changes required for living with a long-term chronic disease (DH 2005e). There is a gap in knowledge around the application of self-management and self-efficacy as applied to people with LTCs especially with people with progressive neurological conditions. The application of self-management and self-efficacy applied to RRMS need to be understood in order to explore how effective they can be to people with progressive LTCs. This research will contribute to this debate by exploring the values and beliefs of people with RRMS and their partners/carers in reviewing the

relationship between the attributes of self-management and self-efficacy in terms of them wanting and being willing to participate in the care process and influences which impacted their behaviour. Section three will now move on to discuss engagement and empowerment and the impact they have on being involved in self-management practices.

Engagement in Health and Social Care

Research into why people with RRMS engage in self-care practices has found that it was because self-initiated strategies gave them feelings of more independence and therefore was an empowerment strategy in the face of illness of an uncertain type (McLaughlin & Zeeberg 1993). There are commonalities with other LTCs in relation to independence, empowerment and self-care. Self-management strategies are chosen and developed by people with MS through experimentation (Robinson 1988). After people spend time engaging in ineffective efforts, they eventually accept that things must change and focus their thoughts and resources on other areas in which their own satisfaction is still attainable (Bishop et al. 2007). However, the need for professional support is expressed by a wide range of people with health needs engaged in self-help and people with MS in particular (McLaughlin & Zeeberg 1993).

Strauss & Corbin (1988) state that helping people with LTCs to develop self-management skills can help them to accommodate increased control and efficacy over their environment and problem solving skills. Self-efficacy asserts personal mastery expectations which are the primary determinants of behaviour change (Bandura 1977), and refers to a person's belief that they have the ability to overcome challenges. This can alter a person's perception and impact of MS in daily life and their capacity for adjustment (Khan et al. 2007). Engaging in self-management may suggest promotion of feelings of personal control across a number of domains (Bishop et al. 2007).

Yet despite this need for independence, people with MS are more likely to discuss their self-help actions with friends, relatives and others with MS, sometimes via self-help groups with others with MS and carers, and less likely to discuss their plans with their doctors or other health professionals. Managing MS is viewed increasingly as a partnership between health and social care providers, people

with MS, and the family and other caregivers. In summary, engaging people with self-management and increasing their self-efficacy of their MS seems to be about tackling the clinical agenda, body and lifestyle adjustment improvements, increasing levels of personal control and where necessary, changing the culture.

Disengagement with Professionals

Communication between professionals and people affected by LTCs has long been recognised as critically important in providing care and supporting self-management (Clark et al. 1995; Von Korff et al 1997). Conversely, many patients find that disengagement with professionals was due to the professionals distancing themselves, power relations, their attitudes and behaviours blocking out the engagement. Some were dismissive of what the patients had to contribute and were not forthcoming with information or resources (Thorne et al. 2004). Thorne also found that when a professional was engaged with the patient problem-solving and care management, there was a feeling of teamwork. This investment supported positive outcomes, and an enthusiasm for working together to create the best decisions possible under the circumstances. Engagement is considered as a highly valuable and important feature of effective health care relationships.

Hibbard et al. (2006) stated that some patients with LTCs are not interested in engaging in healthcare or self-management. They state the stress of MS can provoke a number of responses that could be considered dysfunctional or definitely harmful; for example prolonged denial; disengagement and helplessness; adoption of the sick role; abuse of non-prescription drugs e.g. painkillers and consumption of alcohol and illicit drugs. They believed from their research that the acceptance of LTCs improved self-management and self-efficacy, whereas denial and avoidance behaviour are associated with treatment non-compliance. If people feel that their LTCs are uncontrollable and their treatment options are ineffective, they may feel overwhelmed by feelings of helplessness and disengagement. Such responses may be detrimental to their rehabilitation and quality of life which are important for people with RRMS.

Improvements through engagement

To self-manage and have self-efficacy over their LTC and to enhance their quality of life, engaging people in caring about their health and their RRMS is necessary,

through working in partnership with their formal and informal carers. The ideology of empowerment which lies behind the concepts of self-management and self-efficacy shifts the focus onto the individual and away from structural constraints which lie at the heart of social and economic inequities (Redman 2007). Thorne et al. (2004) have pointed to the way in which the ability of professionals to engage in effective communication is likely to make a difference in whether the consultation reinforces or discourages health actions that will maximise a person's capacity to live positively with a chronic condition. The failure of professionals to engage with patients, as potential change agents in self-management, can lead to a sense of dissonance between prior expectations and actual use of self-help initiatives (Rogers et al. 2004).

In an evaluative research project "The Patient Engagement National Telephone Survey" (Ellins & Coulter 2005) the patients reinforced and corroborated a number of the goals of engagement in their healthcare. The results of this showed that more people want to be active partners in their health and healthcare. The evidence shows that patient involvement improves satisfaction with, and the outcomes and appropriateness of care. There is therefore a willingness to engage. More people would feel the desire to be more involved if they were encouraged, welcomed and made to feel part of the care process through their own self-efficacy. Working with professionals to solve issues rather than being told what they should do. It will be interesting to explore these issues further with people with RRMS.

Empowerment

Empowerment is historically a consequence of self-management; the concept arose from the self-help and political awareness movement in the 1960's (Ryles 1999). The philosophy of empowerment began with specific understandings of the individual within society and the concept of freedom (Traynor 2003; Bauman 1988). From early times, freedom was something granted to one person or group by another powerful individual. According to Kant, humans could claim a new confidence, a new authority through the operation of reason and its principles (Traynor 2003). Enlightenment was an emancipatory project (Foucault 1984). It promised emancipation from the primitive forces of unreason in its various forms, superstition or religion. It asserted the autonomy of the human subject rather than

the subject's relationship of dependence, upon God, for example. It is a project that still consumes a vast amount of energy and its heritage offers perhaps one reason for the persuasiveness of the New Right vision of the freedom of the individual (Hayek 1967; Nozick 1974).

There was a turning point around the 1970s when empowerment and autonomy went from the collective experience to a more individual approach and the effects it could have on a personal level. Through this, personal autonomy was seen as being central to the claims of the modern professional (Freidson 1994). People with LTCs could reconstruct their personal and social identities to rehabilitate themselves and regain a personal lifestyle of their own (Moser et al. 2007). Also as discussed by Kralik (2002) who saw the quest for empowerment and enlightenment as providing opportunities to learn rather than becoming a victim of MS, and saw the understanding of MS as being paramount in increasing empowerment. According to Duval (1984) MS patients tend to manage and control the symptoms of their illness as part of their trajectory which tends to be based upon culturally based norms of values and beliefs. They have independence and self-sufficiency and do not like having to be dependent on others for help. The standard concept of autonomy implies a robust independent individual capable of acting without help (Dekkers 1995).

Autonomy and Empowerment

A consequence of the paradigms of individual autonomy and empowerment are the development of competency processes that allow people to gain control, to have freedom to make decisions with authority and to have choices. These responses are linked to their social, cultural, emotional and psychological needs (Pooley et al. 2001). People with LTCs need to feel empowered in order to recognise the importance of their role and develop skills to actively feel involved in their care processes if this is the choice that they make. (Wilson 2008; Gibson 1991; Thorne et al. 2000). The people actively involved in self-management and development of self-efficacy are working to prevent their condition from interfering and taking over their life through self-control. Working in partnership with professionals with joint decision-making and choice through opting in and out to what is in their own best interest.

Summary of Empowerment

Empowerment has been described as a double edge sword which distinguishes and justifies paternalistic practices; it is simply a change of language and ignores the complex power relations in healthcare professionals-patient interactions (Chapman 1994). Unless these things are addressed and professional 'expert' / dominance behaviours, there will be no further enhancement of patient empowerment and partnership working. Some clinicians may perceive patients' attempts to participate in decision-making as an invasion of their professional territory (Jillings 1992). Paterson and Sloan (1994) found that people with LTCs were often scolded when they told the doctor of a decision they had made in their self-management. Such professional behaviour stems from the biomedical model and the belief that practitioners know best. The contradictions and challenges that exist in the actualising of the concept mean that the discourse of empowerment in LTCs continues to be empty rhetoric (Weissberg 2000). According to Paterson (2001) professionals should be taught how to enact empowering practices and behaviours, as they currently actually inhibit or negate their intended goal. Section Two will now discuss the theories of self-management and self-efficacy behaviours and models of care which can influence engagement and empowerment.

Theories underpinning Self-management and Self-Efficacy Behaviours

Behaviour and behaviour change are central to self-management and self-efficacy and the justification for the application of these models for people with RRMS are worthy of initial discussions within the literature. These will be revisited again in the conclusions. Integrated care in which expertise is shared between patient and professionals is necessary to achieve best possible engagement with behaviour change, problem solving, coping strategies and management (Wilson 1997). These behavioural theories are:

- The self-regulation or common sense model
- Social cognitive/learning theory
- Theory of planned behaviour
- The transtheoretical ('stages of change') model
- Self-determination theory

Source: (Rijken et al. 2008).

The Self-Regulation Model.

The self-regulation model describes how an individual comes to understand their illness and how they control and develop coping strategies to manage it. This theory views the patient as an 'active problem-solver' and emphasises the role of both cognitive and emotional processes in influencing illness perceptions and coping strategies, including self-management behaviours. (Leventhal et al, 1984, 1992, 2001). The beliefs of individuals are important in how they respond to their health and illness. Behavioural intention is the main determinant of human behaviour (Ajzen & Fishbein 1980). This model highlights coping strategies about the symptoms, the causes and prognosis in terms of ways to deal with the stress of the condition and to improve coping with the acceptance and living with the condition. They have also been linked to health related outcomes such as depression and quality of life (Leventhal et al. 1980). Self-regulation theory (Scheier & Carver 2008) assumes two principle and universal goals that humans share – coherence and survival. Self-regulation theory outlines how people pursue goals, striving to maintain self-confidence is an ongoing process of persevering with, refusing or letting go of goals.

Social cognitive/learning theory

Behaviour is influenced by outcome expectations, observational learning and self-efficacy expectations (Bandura 1997). According to Bandura (1986, 1997) behaviour is influenced directly by goals and self-efficacy expectations and indirectly by self-efficacy, outcome expectations and sociostructural factors. Self-efficacy essentially focuses on the individual's personal confidence beliefs about his or her capacity to undertake behaviours that may lead to desired outcomes.

In the social cognitive theory model behaviour is thought to be affected by expectations, with individual's confidence in their ability to do things (self-efficacy) and being positive and self-determined to see things through. This social learning theory has been enhanced by training people to set goals through problem solving as one of the skills of the EPP. The EPP is grounded within the theoretical framework of self-efficacy dealing with problem solving, decision-making, skill mastery, role modelling, persuasion and reinterpretation of symptoms (Lorig et al. 1999). People with LTCs are also taught to increase health related behaviours such as relaxation, exercise, diet, fatigue, breaking the "symptom cycle", pain and

medication management, coping mechanisms, self-care, lifestyle behaviours and communication.

Goals are similar to intentions in other theories of health behaviours; they determine the amount of effort that the individual invests in changing their behaviour and serve as guides to action. Self-efficacy refers to a person's belief in their ability to perform a specific action in a particular situation. It is also influenced by the individual's belief that their behaviours will influence the outcome in some way. According to Lorig et al. (2001) improving the self-efficacy beliefs of patients is a key element of self-management support interventions. Outcome expectations are beliefs regarding the consequences (positive and negative) of performing the behaviour. The theory distinguishes between different kinds of outcome expectations e.g. Social might include approval or disapproval and self-evaluation refers to anticipated feeling of achievement. The theory incorporates perceived opportunities and barriers which are assumed to influence goals. Although social cognitive theory includes a number of constructs, the majority of empirical applications of the theory focus on self-efficacy.

Social cognitive theory and self-regulatory theory hypothesize how beliefs and behaviour specific to physical health can influence emotional and physical outcomes. One influential factor in this theory is the individual's confidence or belief that they have the capacity to undertake the elaborate behaviours required for self-management. People who believe they are able to perform a task are more likely to try the task and overcome their fear at failing at the task, whereas people who do not believe in themselves will tend to avoid the task. People with RRMS are very positive despite the fluctuations in their condition and these two theories may have some influence.

The Theory of Planned Behaviour

The theory of planned behaviour is widely used to study the cognitive determinants of health behaviours (Sutton, 2005; Conner & Sparks 2005). According to the theory, behaviour is determined by the strength of the person's intention to perform that behaviour and the amount of actual control that the person has over performing the behaviour. According to Ajzen, intention is:

'the cognitive representation of a person's readiness to perform a given behaviour, and ... is considered to be the immediate antecedent of behaviour', and actual behaviour control '...refers to the extent to which a person has the skills, resources and other prerequisites needed to perform a given behaviour.' Ajzen 2002, p. 667.

Perceived behavioural control, similar to Bandura's (1986) construct of self-efficacy, refers to the person's perceptions of their ability to perform the behaviour and is assumed to reflect actual behavioural control more or less accurately. To the extent that perceived behavioural control is an accurate reflection of actual behavioural control, it can, together with intention, be used to predict behaviour.

The Transtheoretical Model

Stage theories of health behaviour assume that behaviour change involves movement through a sequence of discrete stages that different factors influence the different stage transitions, and therefore that interventions should be matched to a person's stage (Weinstein et al. 1998; Sutton 2005). This model includes several additional constructs: the pros and cons of changing; confidence and temptation; and the processes of change. In order to integrate these different constructs drawn from different theories of behavioural change and systems of psychotherapy into a single coherent model the term Transtheoretical Model was used. The theory focuses on the individual's motivation or intention to change and how prepared they are to make changes in their actions and behaviours to become more self-managing and in self-control.

Self-Determination Theory

The self-determination theory (Deci & Ryan 1985) emphasises the importance of autonomy, competence and relatedness to others, all of which must be met in order to motivate people. This theory focuses on the difference between controlled and autonomous motivation. Controlled motivation means doing things for extrinsic reasons, such as to make others happy or to receive a contingent reward. Autonomous motivation, in contrast, means doing things for intrinsic reasons or for oneself, such as keeping mobile, being fit and healthy and being positive.

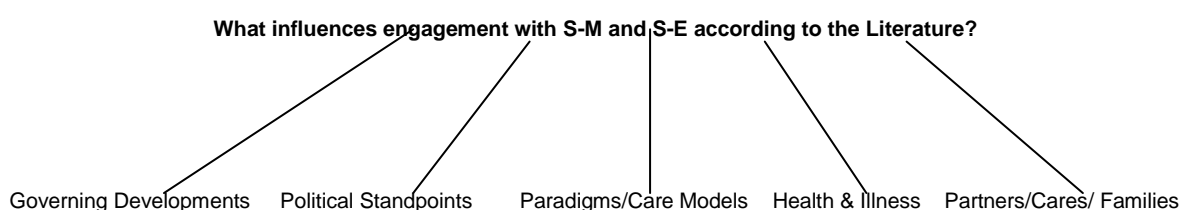
According to this theory professionals should maximise on the motivation of people with RRMS to participate in self-management in terms of supporting their autonomy in initiating behaviour change. This can be supported by goal and target setting and working with the people with RRMS to use their self-efficacy,

beliefs, values and self-determination to demonstrate their autonomy in terms of informed decision-making and choices. The theory focuses on the degree to which human behaviours are volitional or self-determined, that is, the degree to which people endorse their actions at the highest level of reflection and engage in the actions with a full sense of choice (Deci & Ryan 1985). Self-determination is again something that is really prominent and encourages self-control in people with RRMS. The full application of these theories to other LTCs could be an area for further research in terms of fully understanding the theories that underpin human behaviour in self-management in improving their health and control of their condition.

Summary

The impact of these theories of self-management behaviours will be explored further in this research in relation to the theory generated from the research participants. The main themes will be applied to the different behaviours to review the effect they could possibly have with people with RRMS and their formal and informal carers. Further information on self-management support is available in Appendix I which addresses how skills/confidence can be developed to apply these behaviours with outcomes focusing on improved health and lifestyle changes.

Section 3: Influences of Engagement with Self-Management & Self-Efficacy



Chronology of Governing Developments

This section will provide an overview of the UK policies and guidance which have been aimed both at professionals and people with LTCs in order to promote the philosophies of self-management, self-efficacy and independence. This will expand upon the previous sections in determining the political agenda for driving self-management and self-efficacy.

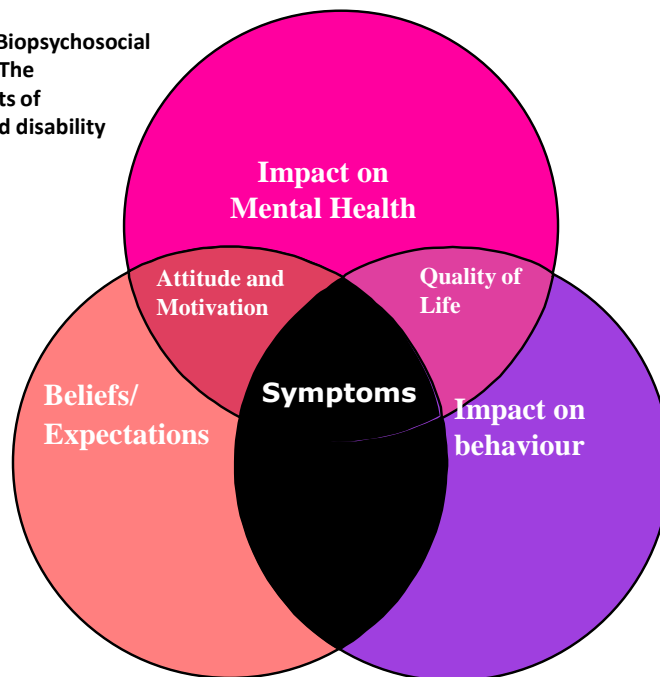
The emerging history of NHS service policy developments have occurred as the self-management and self-efficacy philosophies has developed and models of care have been introduced to support people with LTCs. Over the last decade health policy has highlighted the increasing prevalence of LTCs and ways to support people and encourage increasing self-management and self-efficacy to put people more in control of their own illnesses. The issue of choice and individuals wanting to be involved was not discussed at this stage. A summary of the key influencing documents will be provided in this section.

The 1999 White Paper “Saving lives: our healthier nation” set out the public health strategy for people to be more skilled in recognising warning signs when their symptoms were getting worse. In response to this the Chief Medical Officer was asked to set up a task force to design a new EPP to address the needs of one in three of the total population who have LTCs or disability. The idea being to educate people and entice them more towards self-management and being more involved and control of their own care through self-efficacy.

Expert Patient Programme

The Expert Patient: A New Approach to Chronic Disease Management for the 21st Century (DH 2001) was a programme designed to empower people with LTCs by encouraging patients to take more control of their health. A core element of the EPP is the principle that increasing an individual’s belief in their life will increase their sense and practice autonomy. This in turn will affect all aspects of the management of their condition and lifestyle (DH 2001). It is a lay-led self-management skills programme which employs lay people with LTCs to train others. EPP is an anglicised version of the Chronic Disease Self-Management Program (CDSMP) developed by researchers at Stanford University in the USA (Lorig et al. 2001). Lorig (2005) used the biopsychosocial approach (discussed later in this chapter) to design self-management programmes for people with LTCs that involved both psychological and behavioural education. She states that people who attend these self-management educational programmes on follow-up have better quality of life outcomes: less fatigue, pain and anxiety.

Figure 2.2 Biopsychosocial Paradigm: The constituents of distress and disability



Source: Adapted from Lorig, 2001

The EPP uses the self-management domains (Lorig, 2001) of the biopsychosocial paradigm as set out in Figure 2.2:

- Understanding of healthcare problem: role of healthcare and medicine (bio)
- Emotional responses (psycho)
- Adapting to, and defining new social roles and responsibilities (social).

Figure 2.2 outlines the issues which need to be carefully considered in using the biopsychosocial paradigm model in self-management to cope with psychological and behaviours in symptom management. The overall aims of these EPPs was to improve self-efficacy and to enable participants to more effectively manage their condition, through the development of knowledgeable problem-solving skills and the opportunity afforded by the group to exchange ideas and suggestions.

While interestingly the EPP has been criticised as perpetuating the medical model and failing those in most need (Wilson 2007), it was acknowledged as supportive for the subjective experience of living with a LTCs. The EPP aims to further develop partnership between patients and professionals by identifying the patient as an expert in their LTCs with coping strategies, expertise and knowledge to undertake self-management while working in partnership with the professionals involved in their care. Difficulties were identified by Newbould et al. (2006) with engaging with professionals, particularly GPs, who do not rate self-management

as a priority and hence failure to recruit participants has been causing ongoing concern. In contrast Battersby (2006) states the problems are due to a lack of integration between the EPP and healthcare services and barriers to the uptake of attendance due to lack of referrals from professionals.

NHS Plan

In 1991 the “NHS Plan: a plan for investment, a plan for reform” set out a vision in which the NHS would become a resource for people who looked after themselves to use. NHS Direct helpline was also set up in line with this vision for the future, which again has created mixed responses. WHO also highlighted that all healthcare systems face the challenge of preventing LTCs and treating people who are diagnosed with one or more of these conditions. (WHO 2002). This means driving more care provision away from acute hospital care to high quality care delivered by professional teams with specialist expertise in the local communities. It also means changing the deliverers of care who according to Holman (2005) are part of an era of acute disease prominence with cure as the main goal through physician’s authority and patient passivity, with disease being a passing episode in the patient’s life. The impact of the NHS Plan has not been fully realised as acute care has continued to grow with increasing technology and a focus on investigations and less on communications with patients. This is not helped by LTCs usually having a more gradual onset with the disease unfolding over time with diagnosis uncertainties, therapies are not curative and can have adverse effects and uncertainty and unpredictability are common. LTCs can influence all aspects of people lives including physiological, social, wealth and psychologically with the consequences being very individual to each person.

NHS Improvement Plan

The coordination of services across the health, leisure, housing, education and social care sectors to deliver ongoing care and active participation of people with LTCs is integral to future integrated care management (Wilson 1997). In the UK there has been recognition of the need to develop LTCs services since the late 1990s. The DH has identified better integrated care management of LTCs as a key priority in its 2004 NHS Improvement Plan. This sets out a systematic approach that takes account of the level of support needed by people with LTCs, involving

self-management, disease management and case management. Yet it stipulated the introduction of case management in all PCTs through the appointment of Community Matrons by 2007 (DH 2004d) with the anticipated benefits which included improved quality of care and, by preventing or delaying complications, reduced (emergency) admissions and long stays in hospital. There is very scant evidence available to demonstrate that any of these benefits have been realised.

National Service Frameworks (NSFs)

The Government introduced NSFs to promote better disease management with evidence-based protocols and measurable quality standards. The NSF for LTCs (DH, 2005b) sets out a strategy which seeks to improve health outcomes for people with neurological LTCs by offering a personalised care plans for vulnerable people most at risk. This NSF drives the philosophy of supporting people with neurological LTCs to live as independently as possible. The key themes are independent living, care planned around the needs and choices of the individual, timely access to services and joint working across all agencies and disciplines involved. It also provides specific recommendations to encourage autonomy, self-efficacy and self-management, independent living, and states the interventions are through promoting support by information giving, health promotion, monitoring and communication. The NSF even provides specific recommendations to encourage autonomy and self-management.

There was a new typology of evidence developed with this NSF which for the first time includes expert opinions from users, carers and professionals as well as a broad range of research designs (Turner-Stokes et al. 2006). In addition, there was no focus on specific areas of intervention but rather a holistic approach, addressing all stages of the illness pathway from diagnosis to death. Previous NSFs have been criticised for diverting much-needed resources to meet the NSF targets. In contrast, the new NSF adopted a 'hands off' approach with a move away from centrally allocated funding and prescriptive targets to allow NHS and Social Services to decide how to meet local and national priorities. The NSF is designed to offer much wider application to clinical practice that demand a holistic approach to evidence gathering and appraisal, it also has a more rigorous and transparent evaluation which is being customised by voluntary organisations such as the MSS. This holistic approach to the planning of care can be problematic,

however, because funding to meet the quality requirements must come from existing funding and has to compete with other priorities for limited resources. The NSF aims to transform the way health and social care services support people to live their lives which will require resources. Only time will tell how effective the implementation is through the impact it has on the recommendations set out.

NICE Guidelines for Multiple Sclerosis

The National Institute for Health and Clinical Excellence (NICE) produced evidence based clinical guidelines outlining the range of care that should be available for the diagnosis, treatment and management of MS. These include providing specialist services, a system for rapid diagnosis, a seamless and responsive service, through problem assessment and self-referral after discharge. Many health and social care providers are frustrated that they cannot always deliver the services set out and state repeatedly that people with MS should use them more to request what they are entitled to receive.

Our Health, Our Care, Our Say this White Paper (DH 2006b) set out a vision and package of proposals designed to address the expectations and outcomes that people want for themselves, maintaining a sense of well-being, and leading an independent life. It states that there is solid evidence that care is less effective if people feel they are not in control. The aim again is to shift care from being delivered reactively, often in a hospital setting, towards more responsive community based services, which have implications globally. This involves far more than changing the location where care is delivered. Instead, it involves a whole systems change and joined up working between health and social care services (DH 2007c). This Government White Paper was different to other policy documents as it was based on an extensive consultation process with public meetings and events with key stakeholders to shape the key components of future plans. In particular, people stated that they wanted their professionals to work together and be more “joined-up”, they wanted to receive more care closer to home and that they wanted services that would help them maintain their independence.

Raising the profile of LTCs

The current focus of the DH (England) is on better LTC management, including improvements in clinical care and support in self-care. 'Raising the profile of Long Term Conditions Care' (DH 2008d) emphasises that people with LTCs use disproportionately both primary and secondary care services, with a small number of people accounting for a high proportion of resources. Again they are suggesting changes in the infrastructure, delivery systems and better outcomes. The failings of the acute care models have been addressed with the introduction of the NSFs with national standards against which measurement of progress can be carried out but resources to do so must be found within the current systems.

The problems with many of these publications are they are using the same information in different formats with changing emphasis but they do not take account of the longer term perspective from users, formal and informal carers and they are looking for short-term gains. The gaps in these perspectives have been addressed through this research, across the actual trajectories of people with RRMS and their formal/informal carers. They are all short term strategies which are not followed through or given the necessary drives and resources to implement needed change.

Paradigms and Models of Care adjustments to LTCs

This section explores the different paradigms and models of care that have been applied to LTCs and reviews the applicability to the knowledge contribution to this research. There are a number of theoretical frameworks that attempt to explain how individuals may adjust to threats to health and serious physical illness. Each of these has applicability around the adjustment of the research participants' own MS trajectory. Scientific explanations of chronic illness have focused on the person with LTCs and developed within biomedical or psychosocial frameworks.

Biomedical model

The first scientific paradigm for health originated with development of the machine model of the human body. Descartes (1596-1650) saw the body as a homologue of the machine. Descartes considered illness to be both natural and occurring on an individual basis, and further recommended that investigation of disease be divided into understandable components rather than a holistic approach (Kelman

1975; Larson 1999). The methodologies that developed from this view continue to dominate the practice of medicine today (Kelman 1975). Much of the medical dominance, specialisation, control and power relationships are inherent in these paradigms, which all healthcare professionals seem to be still having difficulties in moving away from in terms of collaborative and integrated care processes. The aim of professional management is to minimise impairment and maximise functioning as the RRMS progresses, and the roles of professionals is the optimal management of decline.

The power of paradigms influences beliefs and action. Paradigms provide a cultural framework within which there is a focus on specific problems, theories and actions which are underpinned by knowledge bases. Foucault's work (1973, 1976, 1980, 1984) is very powerful in this area and has been useful in exploring the discourses of chronic illness. He argues that power relations arise in the discursive practices which accompany the various discourses in which models of adjustment of LTCs are positioned. Foucault (1979) stated that he saw social science as a regime of power that helped maintain social order by normalising subjects into categories designed by political authorities. Wellard (1998) argues that power relations established within these discursive practices and models operate through various technologies of power which operate to make them dominant.

Foucault invites researchers to explore ways in which discourses are implicated in relations of power and how power and knowledge serve in reinitiating practices that regulate what is considered to be reasonable and true (Denzin & Lincoln 2000). This applied to LTCs and care professionals could be an area for further research in light of the slow rate of change for these people with illnesses and coping with social reality. According to Foucault (1965)

“the goal is to describe the interplay between institutional discourses and the dividing practices that constitute local subjectivities and their worlds of experience.” p.12.

The real-world practice requires that we give equal treatment to both its articulative and its substantive engagements (Denzin & Lincoln 2000). The history, dominance and power within the professionals, particularly medicine, has been very strong and has proved difficult to breakdown and cope with engaging expert patients and partnership working.

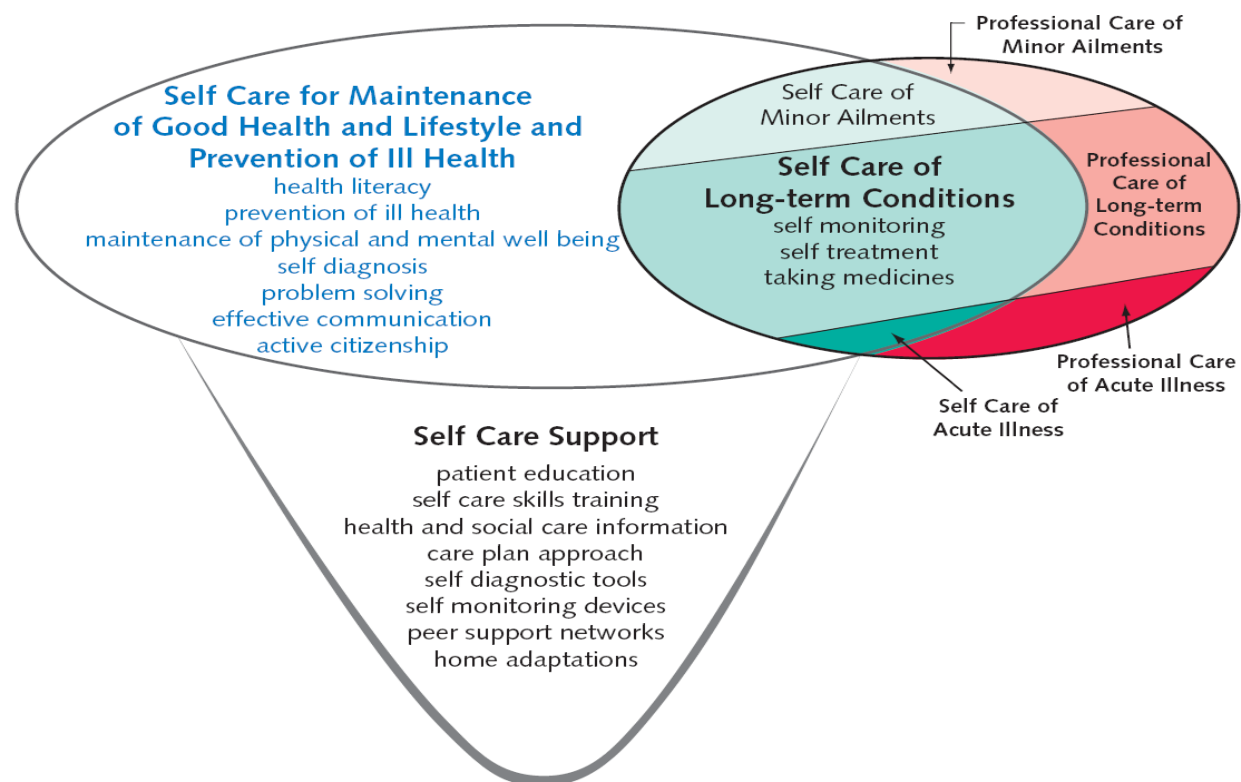
The Chronic Care Model (Wagner 1998) is perhaps the best known framework about care for people with LTCs. The model focuses on linking informed, active people with LTCs with pro-active teams of professionals (see Figure 2.3). It acknowledges that a substantial portion of chronic care takes place outside formal healthcare settings. It suggests that six elements are of central importance in initiatives to improve chronic care: community resources; the healthcare system; patient self-management; decision support; delivery system redesign; and clinical information systems. The components of the model are based on research evidence but there is limited evidence base on any of the models (Kaiser, Evercare, Pfizer and PACE) being implemented in healthcare settings internationally (NHS Institute for Innovation and Improvement 2005). According to WHO (2002):

“A new paradigm will dramatically advance efforts to solve the problem of managing diverse patient demands given limited resources. Through innovation, health care systems can maximise their returns from scarce and seemingly non-existent resources by shifting their services to encompass care for chronic conditions”. p.4

WHO suggested an extension of the CCM to build a framework with building blocks around the patient; the organisation/community and policies in order to create or redesign health systems that can more effectively manage long-term health problems. Most self-management support provided to people with LTCs aims to influence their self-efficacy through behaviour in some way. The healthcare theory is that all people living with one or more LTCs are expected to undertake a variety of activities to manage their condition. This model does have limitations as it is based solely within the biomedical model of care with high expectations and does not recognise the importance of the experiences of the people with LTCs. The CCM challenges the notion of specialised knowledge resting solely with the physician in favour of a broader approach where every member of the care team, including the patient, brings expertise to the table.

Nolte & McKee (2008a) are critical of the CCM stating that it may not provide sufficient practical guidance to assist decision makers with the actual changes to be made in the care process. Hroschowski et al. (2006) identify the barriers to successful implementation of CCM as being that there are too many competing priorities, a lack of specificity of changes and of agreement about the care process changes desired and little engagement of physicians in promoting or supporting the need for change.

Figure 2.2 Chronic Care Model



CCM (Wagner et al. 2001) modified for UK
 “Self Care – A Real Choice” Copyright 2005.

Other researchers focus on specific elements of care or target people who are intensive service users or at greatest risk of hospitalisation (Singh 2005) and re-engineering the delivery processes to allow additional social, psychological and economic burdens to be transferred to the people with LTCs (May 2006). According to Walker et al. (2004) there are three major paradigms that attempt to organise key components of health and adaptation to illness which include the following: the biomedical model which emphasises disease; psychological models of adaptation to illness; and the biopsychosocial models with the latter two emphasising health, functioning and well-being. The theoretical implications for RRMS engaging with self-management and self-efficacy are currently governed predominantly by each domain of knowledge. The latter two will be further explored in the next section which will review the cognitive adaptation and the biopsychosocial models.

Cognitive adaptation model

Taylor (1983) proposed a cognitive adaptation model to threatening events, such as serious and chronic illnesses. Taylor argued that the process of adjustment centred around three themes: a search for meaning in the experience; an attempt to gain self-efficacy through a sense of control or mastery over the illness; and an effort to restore self-esteem. Psychological adjustments are important for research into LTCs such as MS because the adjustment to the illness changes over time. They can also affect cognition, remissions and fluctuations in symptoms that alter over time. The cognitive process of accepting having a LTC is one component of making sense and developing meaning pertaining to the illness. Acceptance of one's condition, including its implications and learning to live with them, has been found to be a common coping strategy among individuals with serious illness and is a crucial component in gaining an optimal sense of control (Shapiro & Astin 1998). Caring by partners/carers is seen as part of family relationships and supporting these relationships is seen as central to enhancing quality of life. In theory, consensus is sought between professionals, people with MS and partners/carers on collaborative management plans but this does not always happen in practice and reality.

Affleck et al.'s (1987) research demonstrated a concern over the association of control and well-being in patients with severe arthritis, they stated while personal

control over medical care and treatment was associated with positive adjustment. People with more severe disease displayed a negative relationship between beliefs of control over the course of their disease. Their adjustment and mood may have represented a limit to the generally positive effects of personal control and that it might be adaptive for some to relinquish beliefs that they can control aspects of their disease in the face of evidence to the contrary. Unfortunately, there is limited research that has examined more positive cognitive adaptation and lifestyle changes as a result of the experience of progressive LTCs (Affleck et al. 1998). This identified gap in the knowledge base should be further explored by this and other research studies. Coping and control are important concepts in this research as they fluctuate with the relapses and unpredictability of RRMS, but at the same time those with the illness still see them as the key drivers to keep them in the driving seat.

The Biopsychosocial Model

This paradigm fits the RRMS trajectory as it uses a framework of adaptation to illness to suggest the same psychological variables which may indeed influence disease activity. According to Salmon & Hall (2003) during the last half-century a psychosocial discourse has gained currency in medicine that can be understood as a response to the limitations of the concept of disease – its constraints both on expansion of medical responsibility and on doctors' ability to withdraw from problematic responsibilities. This discourse is related to the biopsychosocial model (Engel 1977; Huyse et al. 2001) and has more recently been updated further around the concept of 'patient centred care' (Stewart et al. 1995; May & Mead 1999).

The biopsychosocial model has moved on to refer to medicine's attempts to understand patients' illness, and therefore their needs from doctors, in the context not only of physiological abnormality, but also their psychological characteristics and social relationships (Wellard 1998). Strauss et al. (1984) represented chronic illness as an experience of multiple problems that may change but do not go away. Chronic illness is marked by medical crises and prevention and control of these crises require complex social arrangements to address them. Salmon & Hall (2003) state that patients are expected to disclose aspects of their psychosocial

life and to be prepared to change them where necessary to prevent or manage their disease and to become active agents in their disease.

The discourse of coping and control transforms the patient from a sufferer into an agent managing the suffering, from which it is a small step to locating with the patient the moral responsibility to become well (Herzlich & Pierret 1987). Mishel (1988) stated that adaptation to coping can be through biopsychosocial adjustment within the individual's range of normal or usual behaviour which may include psychosocial adjustment, emotional distress and quality of life. Coping therefore refers to the behaviour and meaning people construct around their experience of having RRMS. The validity of psychosocial discourse related to the patient as agent is therefore widely assumed as unassailable.

The recent popularity of the biopsychosocial paradigm model has arisen around the power struggles. Healthcare practitioners need power to fulfil their professional obligations and patients need power to formulate their values, articulate and achieve their healthcare needs and to fulfil their responsibilities (Goodyear-Smith & Buetow 2001). Some of the diseases today clearly show that psychological and social factors contribute clearly to for example cancer and heart disease with common causes of smoking, alcohol, lack of exercise, poor diet and obesity which are all major public health problems and can effect quality of life and lifestyles. Service users, therefore, have a significant role to play in managing their own health and fulfilling their own responsibilities. The biomedical approach takes account of the illness of the patient, the social context in which he lives and the role of the professionals.

Whilst, the biopsychosocial approach incorporates thoughts, feelings, behaviour, their social context, and their interactions with both physiology and pathophysiology into it approach to ill-health and disability. Such an approach does not abandon the biomedical model but it extends it (White 2005). However White (2005) does state there is strong evidence regarding the use of the biopsychosocial model in determining disability associated with LTCs through the patient's illness beliefs and their consequent coping strategies, including their adherence to medical treatments and advice, and secondly through their emotional reactions, particularly fear and depression with consequent

catastrophizing and helplessness. White states that in order to improve the care of people with LTCs, professionals need to examine or be educated to examine their own illness beliefs and consequent communication with their patients. Maximising self-efficacy can be undertaken through utilising the biopsychosocial model with both patients and professional being equally committed (White 2005).

Health and Illness

Illness, like health, is the result of a complex interaction of biological, psychological and social variables. From this perspective, diversity in illness expression is accounted for by the interrelationships among biological changes, psychological status and the social and cultural contexts that shape patients' perceptions of, and response to illness (Gatchel & Turk, 1996). The body and mind are interactive and the effect on one of these will have a bearing on the other and hence in illness suffering from MS not only affects the body but has repercussions in every aspect of the MS sufferer's life. This has an impact on the self-efficacy of the person with MS in terms of engaging them with professionals who take account of their body and their lives. Demonstrating care of the person as well as to their body can help the person with MS to be more involved in self-management and to feel more empowered to be involved in the care processes.

Influence on Partners/Carers and Family

Self-management and self-efficacy also have an impact on the family in terms of how much the person with RRMS can do for themselves. Many people with RRMS are unable to continue working in their current capacity which has a financial impact on the family and this can be a driving influence for them to engage with self-management in order to feel less of a burden on their families. Hakim et al. (2000) estimated that half of the population with MS are not able to work full-time and all those with severe disability who had lost their job because of MS reported lower standards of living and having fewer social contacts than before the MS onset. The loss of employment was associated with difficulties in getting to the workplace, excessive fatigue or visual impairment. An evaluative survey undertaken by Stuifbergen (1997) revealed that 80% of individuals with MS felt they were unable to do the type of work that they wished to do. Pakenham et al. (1997) reported that the MS psychosocial problems were one of the most common problems for decreasing work hours.

Hakim et al. (2000) stated that MS also affected the career of partners, as 36% reported that their careers were affected by the illness of their family member with them having to leave their job, reduce hours or grade, or not gain enhancement or promotion due to their carer role. The social, financial, psychological and physical well-being aspects which can affect partner/carers and their families can impact on the standards of living and withdrawal from social and leisure activities. Engagement with increased self-management and self-efficacy could have an impact on family life and reducing some of the pressures, stress and strains on family members.

Chapter Conclusions

Based upon the literature review undertaking the trajectory and the diagnosis of RRMS is the beginning of a long journey into the unknown. A journey that may begin in hope, pass through periods of elation and frustration and perhaps develop levels of acceptance and resignation. The journey could possibly be improved through engaging in self-management and improving levels of self-efficacy to provide better control and higher confidence. This is what led to the proposal to conduct this research and the constructing of the research question through exploring what has been done and identifying the unanswered questions to justify the need for this research.

Research Question:

How does engagement with self-management and self-efficacy influence the journey of people with RRMS and their formal and informal carers?

It has been argued that the telling of the diagnosis and the explanation of progressive diseases and their treatments can form a map which can provide a route for the pathway of care (Wilson 1997). People may begin the journey with different knowledge and different ways of accepting the diagnosis of RRMS. When people are diagnosed with MS they may make a series of adjustments to their lives over time. Reactions to being diagnosed can be unpredictable and may depend on the individual's coping strategies, and can be influenced by their personality, life experiences, values, beliefs, self-image, self-esteem, active participation, acceptance, motivation, capacity and autonomy. Therefore, these concepts synthesized for the literature review will be further explored through the

conceptual framework (Figure 1.1) and applied to theoretical frameworks to capture the emerging theories from the experiences of the research participants in Chapters six, seven and eight of this research.

One of the objectives for this research study is for it to sensitise health and social care professionals to these individual journeys, so that by gaining understanding of the experiences, frustrations and the tangled web that these people have to go through to get help and support, that the effectiveness, coordination and quality of services provided to these people will be advanced. Creating an awareness of the complexities involved in the interpretations and social constructions of how RRMS is lived will challenge health and social care professionals to balance competing perspectives. One such challenge is the recognition of self-management knowledge and behaviours through increasing self-efficacy and supporting people with RRMS and their partners/carers. By embracing the experiences, confidence and self-control of people with RRMS it is possible to begin to deconstruct the embedded assumptions within the patriarchal health and social care systems.

Optimising care for people with RRMS may have positive impacts on the symptoms, quality of life, health outcomes and satisfaction for them, their partners/carers and families. The constructs of respect, trust and control within care relationships are of critical importance to quality of life with MS. The professionals will receive objective, independently acquired knowledge and experience of the perceptions of people with RRMS and their partners /carers. This research is the exact study which should be undertaken to move knowledge in this field a little further along. It should help in the improvement of care delivery, the optimisation of sharing of advice, recognising empowerment, coping with unpredictability, uncertainty and control mechanisms through engagement in self-management and self-efficacy. Exactly how the care can be optimised is a matter for debate and further research. Therefore this study has explored the why, how, where, when, under what conditions, and with what consequences the phenomenon unfolds. The findings which are grounded in the data will be presented within the findings in Chapters six to eight; and in the discussions, conclusions and contributions to knowledge sections in Chapter nine.

Chapter Three: Theoretical Framework

Introduction

The purpose of this chapter is to discuss how the knowledge that the researcher wants to know, from the research question and aims, will be collected using the most appropriate methodologies as identified through the literature review in Chapter two. The aims of the study will be reintroduced which will then lead onto the discussions of the particular philosophical perspectives and the rationale behind the chosen theoretical framework and methodologies. In setting up the design of this research strategy there was much consideration regarding the conceptual framework (See Figure 1.1) in how the lenses could focus on this topic, the research question and how this could philosophically be undertaken. In developing the research proposal and reviewing the purpose and aims of the research the methods, methodologies, theoretical perspectives and philosophical stance had to be justified.

The research aims

The research was undertaken to find out about life and living with RRMS, in using that knowledge and experience to explore the process of engagement with the conceptual theories of self-management and self-efficacy for people with RRMS. This exploration will be used to generate theory through understanding their perceptions, their experiences and actions. Therefore the aims of the study are:

- To explore the MS trajectory through the individual journeys of people living and diagnosed with RRMS in terms of self-management and self-efficacy.
- To develop an understanding of the engagement processes and the different levels of involvement which drive the willingness to be involved in self-management and self-efficacy of people with RRMS.
- To increase understanding of the attributes of self-management and self-efficacy from the construct and experiences of professionals, people with RRMS and their partners/carers.

A qualitative paradigm using inductive methodologies was adopted to be reflective of the exploration of meanings, reality, processes and perspectives of the research participants. The methods of data collection, that is namely a focus group, semi-

structured interviews, longitudinal studies, self-efficacy questionnaire, personal and reflective diaries will be discussed in detail in Chapter four. (Cross-references to both earlier and later parts of the text will enable the reader to make the links if required). This chapter will concentrate on the methodologies utilised and the conceptual framework. Ontology is the branch of philosophy that deals with the study of being, the 'what is' with the nature of existence and the structure of reality such as peoples' experiences and understanding. There are no definitive answers to ontological questions but, there are those that address the nature of reality, they are important when considering what we can know about reality. Sitting alongside this is a certain way of understanding 'what it means to know' which is the philosophy of epistemology or theory of knowledge embedded in the theoretical perspective and thereby in the methodology (Crotty 1998).

Epistemology is concerned with providing a philosophical grounding for deciding what kinds of knowledge are possible about the nature of reality and how we can ensure that they are both adequate and legitimate (Maynard 1994). Social reality consists of the experiences and knowledge of people, then knowledge of reality will be knowledge of these experiences and understandings (Cormack 2000). The epistemological stance of social constructionism in this study is based on the belief that the participants are the experts who have experience of the phenomenon under investigation. Ontology and epistemology tend to emerge together such as talking about the construction of meaning is to talk about the construction of meaningful reality. Methodologies concerns the questions about the way in which the knowledge can be obtained about what exists and allows the reader to judge the authenticity of the research findings.

In considering the most appropriate methodologies to meet the aims of the study, within the literature review, I explored different philosophies and research methodologies. I considered realistic evaluation (Pawson & Tilley 2006) logic of inquiry. This was reviewed through the utilisation of cycle of theory, hypotheses, observations and program specification within the realist philosophy. Realistic evaluation is based upon a critical realist ontology (theory of how the world is) which can be seen as encompassing both empirical and pragmatic perspectives and those interpretivist approaches which accept the idea that objective exists outside the mind (Kazi 2003). Realistic evaluation suggests there are structure,

mechanisms and causal powers creating the world, which can be explained but not necessarily observed (Wainwright 1997). In general, critical realists argue that social structures impact on the individual's perception of reality and believe they may not always be in a position to change their lives or social circumstances. Following discussion with my supervisors I decided that the realistic evaluation framework might be more appropriate for an evaluation of a group of professionals, but not necessarily for a pure qualitative study with three groups of research participants. This would not enable the achievement of the aims of the study.

The study required a more open-ended approach through utilisation of grounded theory within a qualitative paradigm with social constructionism, interpretivism, symbolic interactionism and grounded theory methodologies justifying the most appropriate way of meeting the research question and aims. Each of these methodologies contributes to the strengths and uniqueness of the research in how they have been utilised to compliment each other and bring philosophical advantages to the findings and decision trail to signpost the reader (see Figures 3.1 and 3.2). These will also be highlighted throughout the thesis.

Open-ended Approach

The research open-ended approach used an inquiry focus for identifying structural as well as contextual, symbolic and interactional influences, allowing for data collection without any assumptions being made. The goal was to develop a substantive theory which could help people better understand and interpret the processes through the MS trajectory. The research question was one that the grounded theory method could investigate based on the notion of reality, the relationship between the knower and what can be known, and how best to discover the reality of the social process, social structure and social interaction. This approach would allow people to be studied in their natural environment where their actions are meaningful and intentional and their social behaviour can be explored.

The study has used a qualitative research paradigm for the exploratory study, data collection and analysis for generating a theory which relates to the engagement

Figure 3.1 : Research Methodologies Decision Making Tree
Open Approach – Qualitative Paradigm

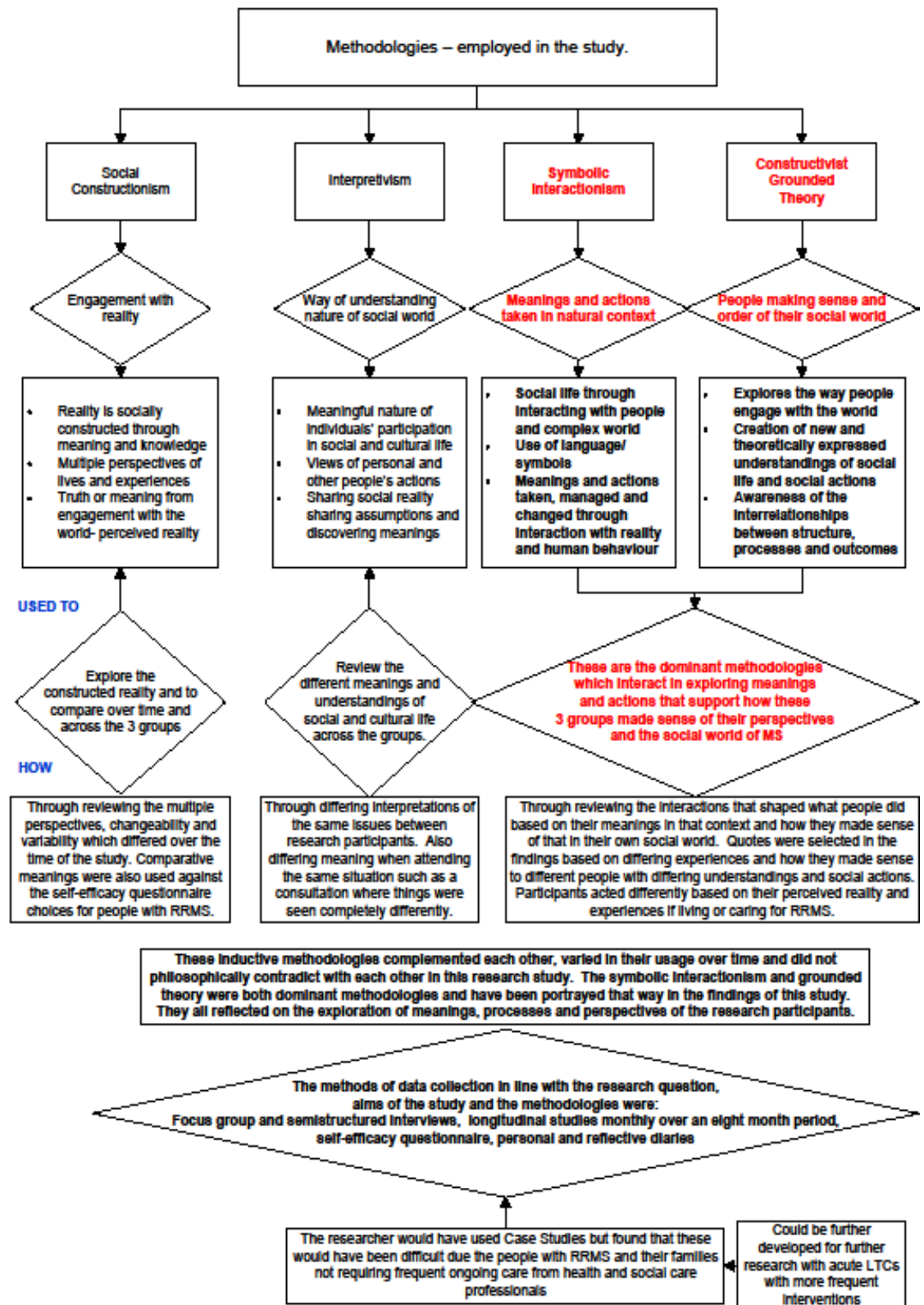
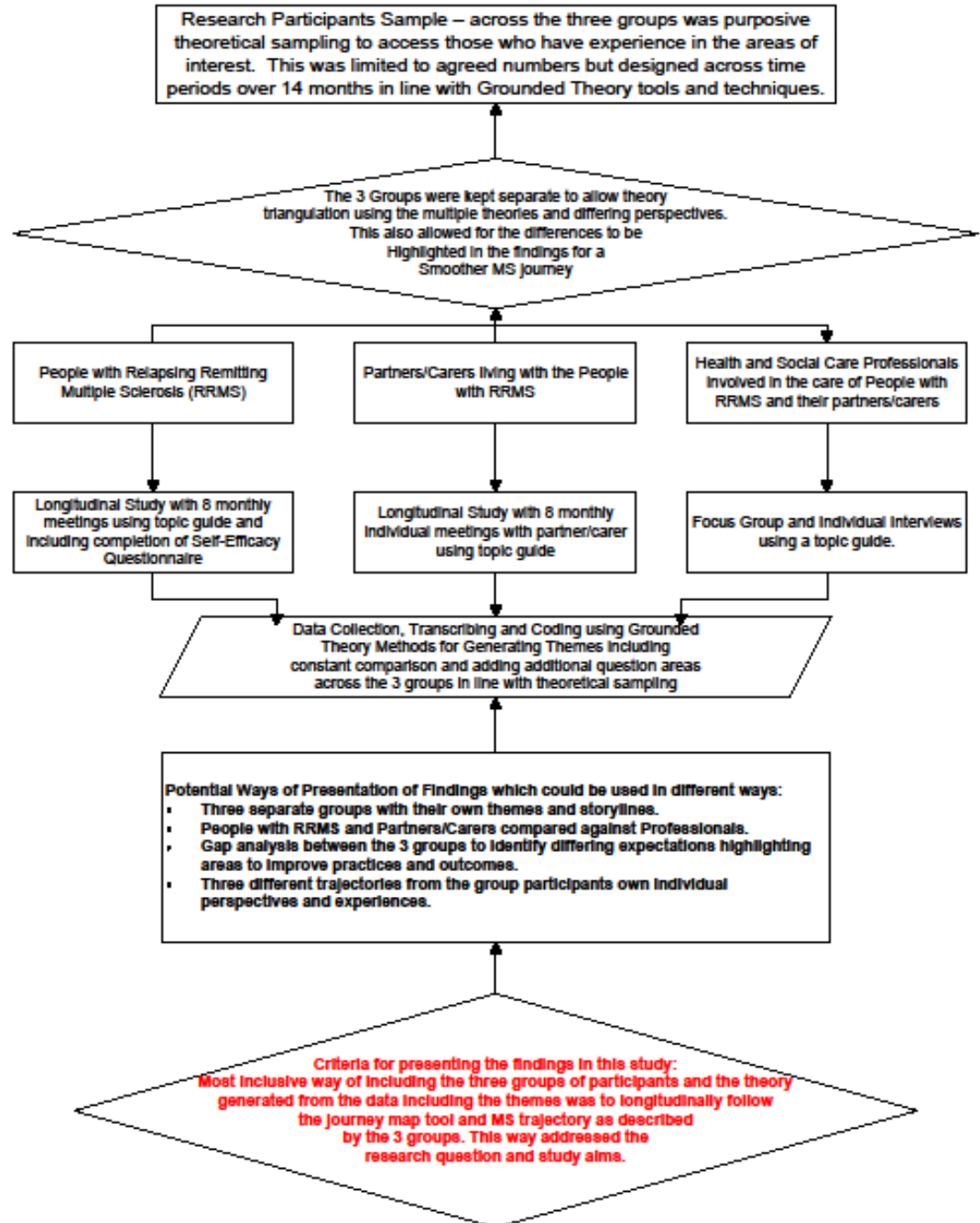


Figure 3.2 : Research Methods Decision Making Tree
Open Approach – Qualitative Paradigm



with self management and self-efficacy of the people with RRMS. This theory will be grounded in the data obtained during the study, particularly in the actions, interactions and the journey of the people with MS, their partners/carers and the professional involved. The focus will be using the theory of knowledge of Social Constructionism to uncover ways in which the people with RRMS, their partners/carers and the professionals participate in their perceived reality of self-management and self-efficacy. As a researcher my role as an active agent was to listen and to investigate the socially constructed meanings that form the participants' realities and behaviours as shared through our discussions together. The idea that multiple realities exist and create meaning for the individuals being studied is a fundamental belief of qualitative researchers. Instead of searching for one reality or truth, qualitative researchers believe that individuals actively participate in social actions and through these interactions come to know and understand the phenomena in different ways. There can be many truths which have been explored in this research. The aims of this study with the three groups of research participants was to understand as fully as possible the nature of multi-faceted reality from the people with RRMS, their partners/carers and professionals involved in caring for people with MS. The researcher's role as teller is to interpret and share these perceptions with the readers based on the data collected without any personal influence on the research, through the use of participant's quotes and their own experiences.

Social Constructionism

A number of perspectives were developed in relation to the theoretical framework and the aims of the research study. Social Constructionism is helpful because it highlights a basic tenet of the approach in it being that reality is socially constructed. Constructionism is an epistemology embodied in many theoretical perspectives, including the methodology of symbolic interactionism, and in most perspectives other than those representing positivist and post-positivist paradigms which are more factually based (Crotty 1998). Truth, or meaning, comes into existence in and out of our engagement with the realities of the world. There is no meaning without a mind, and meaning is not discovered, but constructed. In this understanding of knowledge, it is clear that different people may construct meaning in different ways, even in relation to the same phenomenon. This theoretical perspective highlights the importance of listening to the experiences

through open-ended interviews with people with RRMS, their partner/carers and the professionals, in hearing their stories of living with, engaging in and experiencing self-management and self-efficacy of RRMS. The ontological perspective offered the dialogue of policy, practice and reality of building upon the research of self-management and self-efficacy solutions. This epistemological perspective pointed to addressing the different ways the three groups used their empowerment and enlightenment to promote partnership working relationships. This paradigm shift demonstrates an increase in the degree of alignment between the everyday lives of individuals with RRMS, their partners/carers and the professionals; including the practice, education and research which remains uncovered. Identifying a gap in knowledge, that was explored within this research.

The focus of social constructionism is to uncover the ways in which individuals and groups participate in the creation of their perceived reality and is theoretically and historically founded in phenomenology (Berger & Luckmann, 1966). The origins of Social constructionism can be found in the philosophies of Hegel (1770-1831), Marx (1818-1883) & Mannheim (1893-1947). Under social constructionism the material world is given meaning by being studied by researchers, by those whom they study and is what they study through their own interpretation and analyses. It involves looking at the ways social phenomena are created, institutionalised, and made into tradition by humans. This approach will be an ongoing, dynamic process in which the reality will be re-produced by people acting on their interpretation and knowledge of the self-management and self-efficacy care processes and ways in which the phenomena are socially and culturally constructed. According to Guba & Lincoln (1994) this mode of inquiry offers researchers the opportunity to examine in detail the labyrinth of human experiences as people live and interact within their social worlds. It aims to understand the variety of constructions that people possess, trying to achieve some consensus of meaning, but always being alert to new explanations with the benefit of experience and increased information. As time passes both the participant and researcher constructions mature and become more insightful. This is one of the reasons why the longitudinal studies method (as discussed in Chapter 4) was chosen as part of this inquiry.

Interpretivism

Interpretivism will be the theoretical perspective used to provide interpretation and discovering meanings of the events and phenomena in terms of how the people involved understand their own experiences of engagement and systems of meaning of self-management and self-efficacy. It is historically linked to Max Weber (1864-1920) who suggested that in the human and social sciences researchers are concerned with *Verstehen* (understanding). Interpretivism rests upon the philosophical doctrine of idealism and has a distinct philosophical pedigree to positivism (Williams & May 1996). Interpretive approaches emphasise the meaningful nature of people's participation in social and cultural life. The focus is on the analysis of the meanings that people put on their own and others' actions in order to understand phenomena. Interpretivism is associated with a number of perspectives used in qualitative research including phenomenology, interactionism, feminism, ethnography and action research. This group of approaches emphasises the meaningful nature of people's participation in social and cultural life.

The goal of interpretivism in this research is understanding through symbolic interactionism, which will change and develop throughout the research process. The interpretivist paradigm will be used, which is the way the professionals, people with MS and their partners/carers, view and understand the nature of their social world at the level of subjective experience. This can be built upon their social processes through communication and negotiation created by individuals and social reality sharing assumptions and meanings. Viewing the world through this paradigm seeks to understand the very basis and source of social construction reality and understanding the essence of the everyday world with richness, depth and complexity of the phenomenon. Interpretivism will be the philosophical stance behind the methodology used to provide interpretation and discovering meanings of the events and phenomena in terms of how the people involved understand their own experiences and systems of meaning of self-management and self-efficacy. The focus is on the analysis of the meanings that people put on their own and others' actions in order to understand phenomena. Interpretivism as a philosophy requires explanation of experiences as well as understanding of experiences and in this paradigm the aim is to understand as a way of explaining.

Symbolic Interactionism

Symbolic interactionism is another major theoretical perspective that informs a range of methodologies, and is one of the interpretivist perspectives group. It is derived from pragmatism which explores the understandings and construction of the subjective aspects of social life through human behaviour, the social process and reality through interaction. It focuses on the dynamic relationships between meanings and actions and addresses active processes through which people create and mediate messages. The researcher must be able to actively interact with the persons being researched and see things from their point of view, and in their natural context. Symbolic interactionism looks at how people act towards their physical environment on the basis of meanings that they hold about things and beings in that environment and the complex world of lived experience from their own point of view. It illuminates the relationship and processes between individuals and society as mediated by symbolic communication. Interaction is symbolic because these processes use symbols, words, interpretations and languages (Denzin 1988). The use of symbols to denote objects is an essential human characteristic that allows communication to take place and shared meanings to be derived from this. A pattern of meaning is created and maintained by human association through shared values, traditions and customs.

Meaning is one of the major elements in understanding human behaviour, interactions and social processes. Symbolic interactionism is both a theory about human behaviour and an approach to inquiring about human conduct and group behaviour. Its history spans several disciplines and epistemological roots can be traced to philosophy, education, psychology and sociology (Tourigny 1994). The theoretical basis of grounded theory arose from symbolic interactionism which grounds these assumptions in the most explicit fashion.

As stated by Annells (1996) in the 1920s Thomas and Cooley laid the foundations for symbolic interactionism with their ideas concerning definition of the situation and the looking glass, respectively (Brown 1981). A decade later in 1934, George Herbert Mead (1863-1931), a social psychologist from the Chicago sociological tradition postulated the social nature and origin of mind and self:

“The individual enters as such into his own experience only as an object, not as a subject; and he can enter as an object only on the basis of social relations and

interactions, only by means of his experiential transactions with other individuals in an organised social environment". (Mead 1934, p.225).

Mead defined the self through social roles, expectations, and perspectives set on the self by society and those within society. He sees the self as needing to be appreciated as being situated in interaction with the social world. It is in social interaction that the individual achieves a sense of self and during their childhood. Mead argues that humans come to understand collective social definitions through a socialising process (Annells 1996). According to Mead different individuals will attach different meanings to the same object and an individual will experience the different meanings he himself makes. It is through these exchanges that individuals learn the ways of acting that others expect and so the 'self-consciousness' necessary to engage in social life. The meanings of objects are also derived from social interaction with these meanings being handed in and modified through an interpretation process used by people in dealing with encounters. Symbolic interactionism is the explanation of these processes which leads to the understanding of how and why things are; as these are discovered through finding out about people's lives and circumstances.

Symbolic Interactionism was further advanced by Herbert Blumer (1900-1987), who was a student of Mead, who named it and refined and extended it to become a research approach. According to Blumer, when human beings associate with each other, they are involved in interpretive interaction. This interaction is explained by Blumer (1969) in the following passage:

"Ordinarily, human beings respond to one another, as in carrying on a conversation, by interpreting one another's actions or remarks and then reacting on the basis of the interpretation. Responses, consequently, are not made directly to the stimulation, but follow, rather, upon interpretation; further, they are likely to be different in nature from the stimulating acts, being essentially adjustment to these acts". (Blumer 1969, p.71).

He believed that the social life is expressed through symbols and is intrinsic to symbolic interactionism (Blumer 1969). Meaning is one of the major elements in understanding human behaviour, interactions and social processes. Following Blumer (1969) we assume that human beings act towards things on the basis of meanings that things have for them. There is also interaction going on between the individual and their illness which is explored in this research. Such meanings arise out of social interaction and are mediated and modified through an interpretive process that relies on shared language. Blumer (1969) proposes the methodological position for symbolic interactionism, maintaining that to understand

the world one must analyse it in terms of the participants' actions and interactions. Thus, meaning is accessible to the experiencing individual, although it may remain implicit and taken-for-granted (Charmaz 1995). The researcher must be able to actively interact with the persons being researched and see things from their point of view, and in their natural context (Jeon 2004). Symbolic interactionists seek to know how their respondents define their own situations and it is their task to discover and to interpret their subjective and collective meanings (Charmaz 1995).

Criticism can be levelled against classic symbolic interactionism for ignoring the influences from factors such as institutions, moral structures, and class struggle, therefore producing a resultant distortion of social phenomena (Annells 2004). According to Abercrombie et al. (1986) considerable criticism had been levelled at social interactionism within sociology for not adequately recognising the objective restraints on social action. Denzin (1988) offered a critical assessment against the three central terms within symbolic interactionist thought – social act, language and self. He suggested that particularly the notion of *self* should be relocated within interactionist theory. Glaser (2005) stated that symbolic interactionism was nothing more than theoretical code which was overused by social scientists and he blamed this for the glut of descriptive studies being produced as opposed to grounded theories. Glaser went on to say he thought symbolic interactionism was a kind of backdrop for grounded theory, an assumption that people act and react based on their relationships, but he did not see it as the theoretical coding that could bring a study together.

From the emerging philosophy of social science arose a new argument in regard to the nature, purpose and development of theory. The specific techniques within a research process named grounded theory method were originally developed and refined by two professors of sociology at the University of California in the 1960s; Barney Glaser and Anselm Strauss (Annells 2004). Using a symbolic interactionist perspective, grounded theory provides a way to study human behaviour and interaction. According to Chenitz & Swanson (1986) this approach is particularly useful to conceptualise behaviour in complex situations, to understand unresolved or emerging social problems, and to understand the impact of new ideologies. The methodology of grounded theory emerged as a way to generate theory that would be functional for intended purposes in the world of social science.

Symbolic interactionism emphasises the influence and role of meanings and interpretations in shaping what people do and their experiences. This research has reviewed the language, social interactions and other symbols that mean different things to the players involved in the study and how they themselves understand and then make themselves understood to each other in using the concepts of self-management, self-efficacy, empowerment, knowledge, partnership and locus of control. This was undertaken through observations in the social world through dialogue by face to face interactions through becoming aware of the perceptions, feelings, emotions, behaviours and attitudes of people with RRMS, their partners/carers and the professionals in order to interpret their meanings and intent. The researcher explored how the participants interpreted their identities and their roles within the context of their interactions with each other and with the wider society.

As there is limited theoretical development around the application and meanings of self-management and self-efficacy, as interpreted in RRMS, the researcher believes the grounded theory methodology is appropriate for concurrent data generation and analysis, and the constant comparison of data-to-data, data-to-categories and category-to-category to develop new knowledge in this area. The distinct justification choice of the grounded theory method for this constructivist paradigm study was decided by the research question, together with the consideration of symbolic interactionism within the applicability and feasibility of the method in the context of the phenomena of interest. However, as the focus is on self-management and self-efficacy and there is general knowledge in these areas related to other LTCs, this will not be a purist grounded theory model but a modified version of the approach outlined by Strauss and Corbin.

Grounded Theory

The grounded theory methodology, with its aim to develop explanatory theory concerning common social life patterns, emerged in the 1960s when the goal was to discover a theory that would fit data and work in the real world. Glaser & Strauss (1967) further developed grounded theory drawing on the symbolic interactionist theoretical perspective during their collaboration in research on dying hospital patients. They observed how dying occurred in a variety of hospital settings; they looked at how and when professionals and their terminal patients knew they were dying and how they handled the news. They observed that

studies focused on verifying existing classical theories flourished by deducting testable hypothesis, while research on developing theories grounded in data generating new ideas hardly existed. The roots of grounded theory are epistemologically sound through symbolic interactionism and pragmatist philosophy providing empirical approaches to the study of social life through qualitative research and distinctive approaches to data analysis (Clarke 2005). The underlying assumption of grounded theory is that people make sense and order of their social world even though, to the outsider, their world may appear irrational (Clark 2003). Therefore, grounded theory provides a useful set of strategies for researching experiences of living with LTCs and so was deemed the appropriate methodology for exploring the way people with RRMS, their partners/carers and professionals engage in self-management and self-efficacy.

Grounded theory was initially developed using a systematic methodology in which theory is 'grounded' in data and observation and generated from the data. It was initially positivistic/post-positivist in intent (Lincoln & Guba, 2005); with researchers believing that theory will emerge from the data they collect. This has since become known as the Glaserian grounded theory in recognition of the ontological and epistemological positions of Glaser. Soon after the 1967 publication there was disagreement between Glaser and Strauss on how to do grounded theory. Glaser remained consistent in defining grounded theory as a method of discovery, whereas Strauss moved towards verification. Their different perspectives lie in the data analysis and more specifically in the procedures used.

Both the Glaser's and Strauss's versions of grounded theory use coding, the constant comparisons, questions, theoretical sampling and memos in generating theory. Kelle (2005) stated "the controversy between Glaser and Strauss boils down to the question whether the researcher uses a well defined "coding paradigm" and always looks systematically for "causal conditions," "phenomena/context, intervening conditions, action strategies" and "consequences" in the data, or whether theoretical codes are employed as they emerge in the same way as substantive codes emerge, but drawing on a huge fund of "coding families." Glaser (2001) has stated more recently that conceptualisation is the core of Grounded Theory. Conceptualisation (vis-à-vis conceptual theory) refers to the generation of concepts that are abstracts in terms

of time, place and people; generating concepts that have 'enduring grab' (Glaser 2001). He states that conceptual description is defined as the generation of one concept and then saying everything that one knows about that concept. Cutcliffe (2005) states that while Glaser's view of the centrality of conceptualisation is unequivocal, examination of some studies that claim to use grounded theory methodology shows that they include little, if any, evidence of conceptualisation. This is another difference as a researcher who uses the Straussian approach might disagree with the centrality of conceptualisation.

Mills et al. (2007) state that Strauss' history as a relativist, pragmatist and symbolic interactionist shaped his agenda for evolving grounded theory, as a methodology and as a method, particularly with the development of the conditional matrix as a way of situating action at the centre of his analyses. As stated by Strauss and Corbin (1990) the very nature of the matrix and their paths are opaque until the researcher, with due concern for data, gives them meaning and specificity. According to Strauss and Corbin (1998) "Grounded theory is derived from data, systematically gathered and analysed through the research process. In this method, data collection, analysis and eventual theory stand in close relationship to one another". According to Cutcliffe (2005) it was the fundamental methodological difference between emerging and forcing that led to significant differences between Glaser and Strauss. Glaser (1992) contends that Strauss and Corbin's procedures force data and analysis into preconceived categories and, thus, contradict fundamental tenets of grounded theory. Strauss was much more deeply rooted in interactionism and commented on this as a difference between himself and Glaser (Strauss & Corbin, 1998, 125-126). They emphasised the importance of contextual, symbolic and interactional influences at a micro and macro level. For this research the micro influences are engagement with self-management and self-efficacy, the journey through the trajectory, time of diagnosis and incorporating RRMS into their lives. At the macro level are the political, social, economic and psychological factors.

The Strauss and Corbin approach has continued to be used systematically to develop new concepts, themes and theories by developing inductively derived grounded theory about the key elements of phenomenon and deducing what is going on based on data, literature review and our own assumptions of life.

Grounded theory flexible guidelines help to describe the steps of the research process and can guide the researcher along the path to complete the process with a set of principles and practices that are not overtly prescriptive. Grounded theory describes the construction of theory from data and is particularly suited to exploring the lived human experience (Strauss & Corbin, 1994). The structured organisational model for data collection, analysis and category development helped to bring coherence and clarity to the data processes within this research as set out in Figure 4.1.

Analysis maps were used to set out the differences, meanings and symbols used by the research participants to explore the different meanings, interpretations, symbols used as they engaged with their social reality of RRMS. Using these processes diagrams are radically transformed into maps which are the basis for higher level analysis (Mills et al. 2007). These maps allow researchers to draw together studies of discourse to analyse complex situations of inquiry. The research study was very much about the perspectives of the three groups being studied (people with RRMS, partners/carers and professionals) including the accounts of the journey of people with RRMS. The researcher decided that the analysis maps would provide more appropriate tools for interpretation, understanding, reality and analysis in varying individual situations. These decisions were based upon the need to enrich the research by addressing and engaging with the important differences between the three groups in terms of the complexities of socially and professionally dealing with RRMS.

More recent grounded theory work has been shifting towards more constructivist tendencies (Charmaz 1995, 2000) that focus on meaning-making through enhancing interpretation. These maps are analytical exercises used throughout the research trajectory to provoke the researcher to analyse more deeply across the three groups of research participants. Using these analysis maps has enhanced the research by allowing focus on the elements of different situations and allowing thoughts around these to inform further questions and areas for further discussion until saturation was reached with the research participants.

The purpose of this research study was to explore the experience of living with RRMS in discovering the kinds of concepts which were relevant to generate

theories which attributed to and explained the reasons which help people with RRMS to take control at differing levels across the continuum of engaging with self-management of their care and lifestyle. The roles that their partners/carers and professionals played in the process is also very important to understanding their journeys. The constructivist grounded theory approach allowed themes to emerge from the people with RRMS, their partners/carers and professionals drawing directly from their ideas, interpretation, language, meanings and ways of understanding their own behaviours and attitudes, ideas emerging are said to be grounded in the data and therefore reality. This was undertaken by exploring conceptual labels and categorising them through finding relationships between them and accounting for these relationships through finding core categories (Robson, 2005).

According to Charmaz (1990) Grounded theory studies aim for analytic power and conceptual grasp which synthesize, explain and interpret the data. The rigor of the grounded theory method depends upon developing a range of relevant conceptual categories, saturating those categories and explaining the data. A central feature of grounded theory is its method of constant comparative analysis (Glaser & Strauss 1967), in that the data collection and analysis occur simultaneously and each item of data is compared with every other item of data. This was enhanced through the use of analysis maps in ensuring the depth and richness of the data. The theory inducted is conceptually dense (Strauss & Corbin 1994), that is theory with many conceptual relationships, and these relationships are embedded in a context of descriptive and conceptual writing. Theory was built through making constant comparisons with the data and asking questions of the data. Grounded theory and analysis maps therefore provided new insights into understanding the social processes emerging from the context in which they occurred. The strategy was to continue to develop the theory that was built up around the theoretical framework which was developed to synthesise the perspectives of people with RRMS, their partners/carers and the professionals. The goal of good grounded theory is the construction of tight theory with concepts linked together in explanatory relationships that, in accounting for the variation in data, explain how participants resolve their basic social problem (Schreiber 2001).

This research study has used a modified version of the Strauss and Corbin grounded theory approach using analysis mapping processes; with the constructivist grounded theory through interpretivism and symbolic interactionism reflecting the basic beliefs of constructionism as a paradigm of inquiry. The techniques which enhanced theoretical sensitivity, the treatment of literature as an additional source of data, the data coding, analysis maps, concept and discourse analysis, with categorisation and sub categorisations. The aim was to discover the kinds of concepts attributed to the relevant generating theory and the understanding of how professionals, people with RRMS and their partners/carers engaged with self-management and self-efficacy. The developed theory accounted for much of the relevant behaviour, constant comparative analysis, data coding and conceptual development and density using triangulation of the different types of data collected through the chosen methods. Use of the analysis maps helped to explore a range of difference and variations in the data enhancing the modified grounded theory approach.

Sampling in Grounded Theory

The use of purposive sampling, or sampling with prearranged criteria (Patton 1990) was used to drive theory about the realities of living with RRMS and engaging with self-management and self-efficacy. In order to generate concepts and conceptual categories from the data analysis, the need for sampling specific data sources continues until each category is saturated. Within grounded theory this type of purposive sampling is referred to as theoretical sampling. That is, the persons interviewed are chosen to help the researcher formulate theory. Sampling strategies have an impact on the scientific rigour of the research in terms of rigour and trustworthiness. Chenitz and Swanson (1986) state the theoretical sampling is based on the need to collect more data to examine categories and their relationships and to assure that representativeness in the category exists. This research study explored multiple realities of people with RRMS, partners/carers and professionals over time through longitudinal studies which allowed for constant comparisons and further questions to be generated. This use of theoretical sampling was built upon the experiences of the participants over time through influencing and guiding data collection at each stage of the project which was deemed to be important in this project as this was an evolving process. Hence

Table 3.1: Sampling Strategy of People with MS

Criteria for Sample		Descriptor
Willingness /Volunteer	Essential	Consent at each meeting
Age	Over 18 years upwards	Full range
Gender	Male and Female	Mix of both if possible – MS higher incidence in women
Stage of MS	Full continuum	Relapsing Remitting MS
Health Status	Well enough to participate	To be monitored
Partner/Carer	Willing to be involved	Informal support
Language	Able to speak English	Due to time constraints

the acceptance of limitations and principles of theoretical sampling not being predetermined was considered in order to follow the same people over time.

The aim of theoretical sampling is to maximise opportunities to compare events, incidents, or happenings to determine how a category varies in terms of its properties and dimensions. Using a predetermined sample may have some limitations but across the longitudinal studies there are cumulative opportunities to compare concepts and to densify categories through constant comparisons and asking further questions of research participants across their evolving journey. Theoretical sampling is cumulative, building and adding on to previous data collected and analysed, prior to return visits. It shapes further data collection through pursuing development of conceptual ideas rather than building general information. This is to maximise the opportunities to discover variations among the concepts and to help in generating conceptual categories in terms of their properties and dimensions and then to formulate and direct the evolving theory through saturating those categories. Sampling and analysis are a cyclical process and will occur sequentially with analysis guiding the data collection. Each category needs to be tested against incoming data as a full range in a category is sought. Once no additional data is to be found whereby one could further develop properties of a particular conceptual category, theoretical saturation is achieved.

Sampling Recruitment and Strategy

The research was undertaken in a Northern PCT where access was given to a multi-professional Neurological Rehabilitation Team (NRT) and the primary care team who care for people with progressive LTCs. The PCT were supportive of the research being undertaken and did not impose any limitations on the project. The health and social care professionals were chosen first in order for the researcher to seek perspectives of the usefulness of the proposed research, to get a good grounding in the local service provision for people with RRMS and the structural set up of multidisciplinary working between primary and secondary care. Also to gain access to people with RRMS who met the criteria of the sampling strategy as set out in Table 3.1.

During an initial meeting and discussions with eight members of the NRT they all expressed interest in the research and a desire to be involved. They felt that the

research study would be very useful to both the professionals and the people with RRMS and had the potential to improve services for them and the users. A purposeful sample from the potential team of volunteer professionals' physiotherapist, occupational therapist, speech and language therapists, Primary Care Team – community matrons/district nurses, and specialist continence advisors were recruited for the Focus Group. The aim was for the sample to be representative across the professionals who cared for people with RRMS with a mixture of the different disciplines to provide a range of perspectives and expertise. The volunteer professionals who were not able to attend the Focus Group were interviewed individually to ensure their input into the research was captured. Interviews were also held with GPs, a Continence Specialist Nurse; a Consultant Neurologist and an MS Nurse Specialist at the Regional Centre; a Rehabilitation Consultant and MS Team Leader Specialist Physiotherapist at the Rehabilitation Centre; and with a Senior Social Worker and Welfare Benefits Officer from Social Services. Further discussions took place with professionals for further issues to be explored following the ongoing constant comparison of the data across the study.

Based on the research question people with RRMS at various stages of their diseases, and their partners/carers were invited to participate. The sample identified were both male and female (bearing in mind that women are almost twice as likely as men to develop MS), and their partners/carers who were drawn from the Northern PCT. They were identified as meeting my criteria by the NRT and the local MSS. The sample was across the continuum from recently diagnosed to those who have had RRMS for a number of years. The criterion was based upon those who are able and well enough to commit to a minimum of eight meetings, those who spoke and understood English, and those who had a partner/carer supporting them. The commitment required for the people with RRMS and their partners/carers, was to be interviewed individually as part of the longitudinal studies, for approximately 1 hour each month over a minimum of eight months. Letters and information sheets were sent by me to 20 people with RRMS and a sample of the required 6 people volunteered to take part. Details of the actual sample are set out in the Sampling frame in Tables 3.2 and 3.3 which provides brief details of the people with RRMS and their partner/carer using pseudonyms. The people with MS were 3 male and 3 female with an average age

of 44.5 years, a mean duration with RRMS of 9.6 years and a time interval from recognition of early symptoms to actual diagnosis of between 4 months and 6.5 years. The group of people who committed and gave their time to this project were informative and demonstrated commitment and support. They were all people who welcomed the researcher into their homes and shared their experiences and MS journeys with enthusiasm, were open and honest and looked forward to the meetings.

If the research was going to be replicated there are various alternative dimensions which could be preferenced which are highlighted here. Inclusion of people who did not speak English would be useful and may have raised more cultural awareness; a theoretical sampling method could be used recruiting more people with MS based on emerging concepts and constant comparison of the data collected from different people; partners/carers could be selected in the same way and not necessarily connected to the actual sample of people with MS and it may be worth considering recent newly diagnosed people in the first five years of their symptoms and diagnosis as there was a changing pattern with MS 3. A case study methodological approach may also be useful if the professionals caring for the people with MS and their families could be identified and included as part of the sampling recruitment process.

The researcher is indebted to all the research participants for their time, social interaction and commitment and was privileged to meet such a great group of people. The researcher was also aware of the importance of disengagement which needed to be achieved when the project was finished and the researcher 'leaves the field'. This was handled with empathy, tact and diplomacy in order to leave the close relationship that had been established. The researcher was also aware that at future MSS events and MS meetings she would meet these people and she also intends to undertake a feedback session on the research findings once the PhD process is complete.

User involvement in the study sampling

The researcher joined the professional network group of the MS Society, attended local and national MS meetings and network conferences and has obtained

publications from the MSS. She also attended the Expert Patient Programme held within the PCT to review the information being shared and the group participation. Discussions with people with LTCs including MS demonstrated a high level of interest in self-management and self-efficacy. They expressed concerns and frustrations about areas they wanted to be more involved in and tasks and interventions where the professionals did not always have time or want to listen to their views or desires to be more involved. Some of the group expressed wanting more power and control over their RRMS but felt disempowered and wanted more information and involvement. People with RRMS (including professionals with MS) were given the information sheet and topic areas to make comment and to discuss the applicability to the sample group. They also endorsed the suggestions of numbers in the sample and the three groups i.e. people with RRMS, their partners/carers and health/social care professionals. The people with MS felt it was important for their own partners/carers to be involved because they shared their journey and would have so much to offer the research study. Members of the group stated they would be very interested in the outcomes of the research study in terms of the findings and recommendations.

It was the researcher's responsibility to select methods of communication that ensured the potential participants were fully informed before deciding whether or not to join the study. All participants received information leaflets and written informed consent was obtained in person prior to interviews or focus group. Informed consent was an ongoing process which was continually negotiated and agreed with the people with RRMS and their partners/carers at the start of each of the eight sessions (samples of consent forms are in Appendix II). All participants were assured that confidentiality, integrity and anonymity would be adhered to as far as possible. The partners/carers identities would not be disclosed and they would not be linked to the person they are caring for, they would only be referred to as Pseudonym, Carer. Pseudonyms were used to protect all participants and any information that was deemed to make participants identifiable was not included. The audio recordings were transcribed verbatim and given a numerical indicator. The research was being undertaken to benefit professionals, people with MS and their families in promotion of their interests and well-being. The professionals, people with RRMS and the partners and carers all had unique voices as individuals and it was important to capture these within the research

findings. The researcher listened to the three groups of participants building theory around their perspectives and generating new knowledge throughout the project.

Ethical considerations.

The research study has been conducted in accordance with Northumbria University's Ethics Committee, National Patient Safety Agency and the Primary Care Trust's ethical requirements for research studies. These are to protect the participants' interests, trust and participation by ensuring that research is conducted to high ethical standards. Attention to the protection of the research participants and their rights implies a responsibility on the part of the researcher to contribute to the empowerment of the respondents and their privacy, confidentiality and preventing coercion. The challenge was, with a small sample of 6 individuals and their partners/carers that the comments would be kept confidential. Discussions took place with regard to possibilities of the information being potentially attributable to individuals. All participants were made aware of this and accepted that this may be difficult. This placed a greater duty on the researcher to develop approaches to anonymise and these were discussed with the participants. In order to ensure confidentiality during the lifetime of the project, all research material will be securely stored. At the end of the research study all digital audio recordings will be destroyed.

The issue of disengagement from the research participants was also perceived as an ethical issue. I became aware that disengagement might be an issue but the period of dialogic process was over and it was necessary to reduce the amount of time spent with the research participants. The literature offers little guidance for researchers on sensitive subjects where participants are at risk of psychological distress. The researcher did this in a progressive way in order not harm the participants.

Table 3.2: Actual Sample of People with RRMS

Research Participant	Age	Gender	First recognised symptoms	Year of Diagnosis	Age at Diagnosis	Denial	Mobility aids
MS 1	45	F	1993	1993	30	Yes	Yes
MS 2	35	F	1999	2004	31	No	Yes
MS 3	47	M	2006	2006	45	No	Yes
MS 4	53	F	1985	1988	33	Yes	Yes
MS 5	30	M	1999	2001	23	Yes	No
MS 6	57	M	1992	1998	47	Yes	Yes

Table 3.3 Sampling Frame overview of research participants (using pseudonyms)

Name	Age of person with RRMS	First recognised Symptoms	Diagnosed	Interviews	Dates	Brief Comments
Amy and her husband	Amy aged 45	1993	1993	Interview 1	30/01/2008	Amy continued to work for 12 years and coped very well. Started on DMTs in December 2005 but developed antibodies and started to notice changes and the start of her physical limitations. Her mobility and tremors are causing ongoing problems. She started on Tysabri in April 2008 and is hopeful for mobility improvements.
				Interview 2	25/02/2008	
				Interview 3	28/03/2008	
				Interview 4	08/05/2008	
				Interview 5	09/06/2008	
				Interview 6	09/07/2008	
				Interview 7	04/08/2008	
				Interview 8	28/08/2008	
Michelle and her husband	Michelle aged 35	1999	2004	Interview 1	13/02/2008	Michelle was investigated for balance and middle ear problems which led to an MRI which detected her RRMS. She is able to walk with a stick, has some cognitive and depression problems but generally copes well and looks after herself and family. She keeps fit and enjoys meeting others with MS.
				Interview 2	14/03/2008	
				Interview 3	15/04/2008	
				Interview 4	07/05/2008	
				Interview 5	18/06/2008	
				Interview 6	23/07/2008	
				Interview 7	20/08/2008	
				Interview 8	01/10/2008	
Richard and his wife	Richard aged 47	2006	2006	Interview 1	06/02/2008	Richard is more recently diagnosed and is articulate in organising what he requires in terms of services. He has a history of relapses over bank holidays and has had a couple of bad relapses. He lives in an upstairs flat with his wife and son. He is unwell and unable to continue with the research discussions.
				Interview 2	14/05/2008	

Name	Age of person with RRMS	First recognised Symptoms	Diagnosed	Interviews	Dates	Brief Comments
Mary and her husband	Mary aged 53	1985	1988	Interview 1	08/02/2008	Mary was diagnosed a number of years ago and has lived with RRMS in her background. She has not allowed it to interfere with her family and has coped really well. She still drives and she walks with a stick and self-manages well. Her mobility has deteriorated and she attributes that to MS & getting older. She has repeated urinary infections
				Interview 2	12/03/2008	
				Interview 3	08/04/2008	
				Interview 4	07/05/2008	
				Interview 5	10/06/2008	
				Interview 6	28/08/2008	
				Interview 7	24/09/2008	
				Interview 8	08/10/2008	
Ian and his mother	Ian aged 30	1999	2001	Interview 1	12/02/2008	Ian is fully mobile and does have some cognitive problems particularly with his memory. He lives alone and copes well. He is desperate to find employment and is trying very hard. He has had a couple of relapses this year mainly with optic neuritis. He likes his independence.
				Interview 2	11/03/2008	
				Interview 3	08/04/2008	
				Interview 4	06/05/2008	
				Interview 5	16/06/2008	
				Interview 6	08/07/2008	
				Interview 7	05/08/2008	
				Interview 8	01/09/2008	
David and his wife	David aged 57	1992	1998	Interview 1	31/01/2008	David broke his neck in an RTA and his MS symptoms were noticed and not thought to be due to his injuries. He is now mainly in a wheelchair due to his physical limitations but does try to walk for short distances. He is mentally very alert and maintains his mental ability with chess/reading etc. Use his scooter to get out. Lives with his wife and their families
				Interview 2	10/03/2008	
				Interview 3	10/04/2008	
				Interview 4	07/05/2008	
				Interview 5	05/06/2008	
				Interview 6	03/07/2008	
				Interview 7	24/07/2008	
				Interview 8	22/08/2008	

Role of the Researcher

In qualitative research, the researcher and the research participants have a special importance. The researcher and participants and the researcher's communication competencies are the main "instruments" of collecting data and of recognition (Flick 2009). Like the research participant, the researcher had an important active role to play in the research process and inevitably she has the potential to influence many aspects of the research, which has to be managed through being reflective and reflexive. Unlike post-positivist researchers, grounded theory researchers are personally involved in every stage of the research with the result that they exert greater influence on the research. Reflexivity is an awareness of the ways in which the researcher as an individual with a particular social identity and background has an impact on the research process. Ahern (1999) states the ability to put aside personal feelings and preconceptions are more a function of how reflexive one is rather than how objective one is. It is not possible for researchers to set aside things about which they are not aware. In this research an audit trail was kept with full records of the activities while carrying out the study and the researcher was continually reflecting on what she had heard and making entries in her reflective diary. Reflection on the diary entries established a process of knowing, and identification of assumptions and biases that may influence the representation of the research participants' experiences. The audit trail included ongoing review of all the researcher's raw data, transcriptions, field notes, reflective and personal diaries, and details of coding and data analysis.

All researchers have preconceptions whether they come from previous experiences or pre-existing theory and it is important for them to actively work to prevent these from narrowing what is observed and theorised. It seems each methodology suggests that awareness of the tension between distancing and immersion is necessary in order to establish rigour and trustworthiness (Koch 1995). The researcher's own experience will inevitably be involved in terms of historical, cultural, personal and professional background (Gadamer 1976). The researcher of this project, as a senior nurse and healthcare director, may have brought pre-understandings and prejudices to this research study and no attempt could be made to disguise these, so it was important for her to make her concerns and position clear.

Reflection and reflexivity was considered at every stage of this research process. The researcher's role was subject to the same level of scrutiny as the research itself with the researcher's critical gaze turned in on one's self. (Koch & Harrington 1998; Rice & Ezzy 1999). This process of critical self-reflection was a valuable way of adding credibility to the research by adding greater insight and depth through trustworthiness and rigour. In undertaking the research I had a continual focus on the requirements to demonstrate scientific rigour throughout all stages. The researcher's role was as a listener and a teller; as a listener she heard the perceptions, words and emotions of the research participants in sharing their experiences across the continuum of engaging with the self-management and self-efficacy of RRMS. As a teller she re-listened to their interpretations and interactions and analysed the data and information without adding any personal or professional bias as this is the area where she could have greater influence in the research process. She also was responsible for re-telling the stories around the generated themes throughout the findings of the research.

The collection and interpretation of data and information was constructed with sensitivities to the researcher's personal and professional prejudices. Prejudices are the conditions by which we encounter the world as we experience something. We take value positions with us into the research process. Koch (1994) states that these values, rather than getting in the way of research, make research more meaningful. To establish trustworthiness in the research study, Guba & Lincoln (1989) appeal to four suggested criteria of credibility (confidence in the truth of, and interpretation of the data); dependability (the decision trial which is dependent on credibility); confirmability (objectivity with the data's accuracy, relevance and meaning); and transferability (generalisability and transferability of the research to other or the same populations). According to Polit & Beck (2006) in the later writings of Lincoln & Guba (Guba & Lincoln 2005) a fifth criterion was added which was more distinctively linked within the naturalistic paradigm which was authenticity (the researchers fairly and faithfully showing a range of realities in participant's feelings and lives). These first four criteria have been used extensively over the past twenty years, but the debate over rigour continues to challenge and transform our research practice.

Credibility was aimed at by developing a construction of the situation (the experiences of people with RRMS, formal and informal carers) which relied on fusing all sources of data. I have strived to establish confidence in the truth of the findings in this research by checking the key issues with my research participants and in demonstrating the context of the research. The ongoing involvement over the eight month period with the people with RRMS and their partners/carers helped to build up truth and confidence through a trusting relationship. This allowed ongoing observation facilitating the collection of more detailed, accurate and meaningful information. I believe this had an impact on the quality of the data collected and therefore the quality of the research findings. Peer debriefing has also taken place through the presentation of my findings at conferences for peer evaluation which helped to clarify my thinking and opened the work up for the scrutiny of peers. My supervisors also provided feedback and discussion and made a significant contribution to my thinking and the work presented through this thesis. Dependability was assured by the researcher having all the conclusions firmly grounded in the data or explained by the researcher's interpretive scheme. A decision trail provided a means for the researcher to establish audit trail linkages (See Figures 3.1 and 3.2). By providing the decision trail the reader should be able to consider if the data collection and analysis were performed with sufficient rigour. I am also very highly critical of my own work and my decisions have been made in an attempt to add strength to the scientific rigour. A personal and reflective diary was kept throughout the research study which was used as a source of information about the progress of the research and the decisions made. These were referred to repeatedly during the presentation of the findings and subsequent discussions. Dependability was also strengthened by drawing on multiple data sources, each used to add depth by contradictory and complementary data across the three groups of research participants.

Confirmability was achieved through all data being treated as reproductions of reality; along with the audit trail these provided the appropriate criteria for rigour and trustworthiness of the data. In Chapters six to eight I have used direct quotations from the data transcripts to support the themes and the theory presented in this thesis. Confirmability was also strengthened by seeking confirmation from the participants that the theory was an accurate reflection of their own experiences. Transferability was provided through description of the

research setting, those involved in the research and the way in which the research was undertaken. It is then up to the reader to judge if it might be appropriate to transfer the findings, or part of them, to another population or whether they should undertake additional research in their own setting. The researcher aimed to help the reader by ensuring that the decision trail was both clear and comprehensive and by providing a full account of the theoretical framework on which the study was based. Although it was not the aim of this research to provide generalisable findings, knowledge gained in this setting may be transferable to another setting. In this thesis, the reader is provided with all the information required to make this judgement. Authenticity was obtained through the researcher helping the reader to live vicariously through the lives being described across the MS trajectory and to develop a heightened sensitivity to the issues being explained through inviting the reader to accompany me on the RRMS journey. Again the reader is the best judge of this in terms of how it makes them feel, experience and see the context of the lives of people with RRMS and their formal and informal carers.

Theoretical Perspectives

Knowledge of the literature can enhance sensitivity as to what to look for in the data and assisted in formulating questions were used during the focus group and individual interviews. It was also used as data or for making comparisons, as it can act as the foundation for generating theory. The prior understanding of the literature can provide techniques for questioning the data. Strauss & Corbin (1998) state that the important point for the researcher to remember is that the literature can hinder creativity if it is allowed to stand between the researcher and the data. If it is used as an analytical tool, then it can foster conceptualisation. The literature review was an ongoing process at the beginning and end point of data collection in the research process thus providing a dynamic interaction between the research problem and the theoretical perspectives. As new discoveries were made within the data, reviewing the literature provided a context within which to understand the findings. The goal was one of theory generating by testing out ideas as the data is being collected and analysed through analytical induction and then further data will be collected through theoretical sampling to test out the ideas.

Conclusions

Some key philosophical debates around research have been explored and conclusions drawn regarding the most appropriate approach for this research study. A modified version of constructivist grounded theory is justified through a symbolic interactionist approach in presenting the chosen philosophical perspective as the understanding of meaning, through contextual, symbolic and interactional influences, by the research participants is central to the research. The emphasis in grounded theory is on the importance of deriving theories through themes and categories from the data to provide explanations of social structures and processes inductively by grounding explanations for observed phenomena in the data.

My pre-understandings were built upon the awareness of rigour and trustworthiness including having an objective approach to managing and setting aside my own presuppositions and undertaking cross data analysis. My proposed management strategy is to favour the constructivist interpretation approach of Guba and Lincoln (1989) with the need to balance distancing with immersion by suggesting that the presentation of the findings are the result of competing socially constructed realities, of which there are many within an interaction or situation. I was also self-aware of my own perceptions and beliefs by accepting and taking this awareness through the interpretive journey. Koch (1999) suggests that, you should take this self-awareness, this sense of reality as a human being in the world, with you into the interpretative act.

When asking your participants to tell their story, you accept that this story is their construction of reality. This self-awareness helped me to think critically about the ways in which my knowledge and experiences could inform or influence the research study in any way. This process was consistent with symbolic interactionism using the interpretive approach advocated by Denzin (1992) and actively engaging in the analytical process which moves iteratively from data to theory and theory to data through my experiences and interpretation of the research process. There are critical turning points in the MS trajectory illness transition experience. Story telling may be the turning point as participants feel validated and this enhances the experience of their life. The process of telling stories about life with MS, a critical turning point lies precisely in telling it, and the

experience of being heard for the first time was validating for their sense of self and identity. The sharing of stories provided a potent means for initiating self-reflection and critical action and this aspect should not be underestimated. Stories are social constructs as they emerge from social interchange. If health and social care professionals are to understand the process that facilitated people to move towards incorporating MS into their lives, enhancing self-management can make strides towards this.

Ethical aspects of the research study in terms of protecting the rights, interests, trust and participation of the participants through the research approach have also been considered in this chapter. In keeping with the current guidelines on research governance the study has been designed to ensure that it meets the key criteria of scientific validity, welfare of participants and respect for their dignity and rights.

Chapter four will discuss the appropriate methods of data collection which were selected to meet the philosophical perspectives of social constructionism, symbolic interactionism and grounded theory in the research design. The importance of deriving theories and explanations were considered in the ways that the data could be collected in the most effective ways. The concepts of scientific rigour which have had a continual focus throughout all the stages of the research will be considered further in Chapter five.

Chapter Four: Methods Used.

Introduction

The purpose of this chapter is to take the identified means of collecting knowledge through the methodologies outlined in the Chapter three, and to utilise the appropriate methods to collect the data through the means by which the new knowledge is available. The methods of data collection used in this study, namely a focus group, semi-structured interviews, longitudinal studies, self-efficacy qualitative questionnaire, personal and reflective diary are discussed in this chapter. The development and implementation of each method is outlined in relation to the completeness and confirmation it conferred to the study as a whole. These methods were chosen based upon the methodologies and research question which were formulated around an open-ended approach to allow data collection without any assumptions being made. Throughout the discussion consideration is given to the various steps taken to ensure, as far as possible, that the research was rigorous in conduct through systematic and transparent data collection by the most appropriate means.

The research design

The research study involved three phases. The first phase was with the professionals in order for the researcher to seek perspectives of the usefulness of the proposed research, to get a good grounding in the local service provision for people with RRMS, the structural set up of multidisciplinary working between primary and secondary care and to gain access to people to the people they cared for with RRMS. The second phase involved spending time with people with RRMS and their partner/carer separately in their own home on a monthly basis over an eight month period of time. These open discussions involved semi-structured interviews using a topic guide which was added to across the interviews based upon constant comparisons and new areas which were discussed and verified across the six groups. The third phase was the data generation, analysis and evaluation which will be discussed in Chapter five.

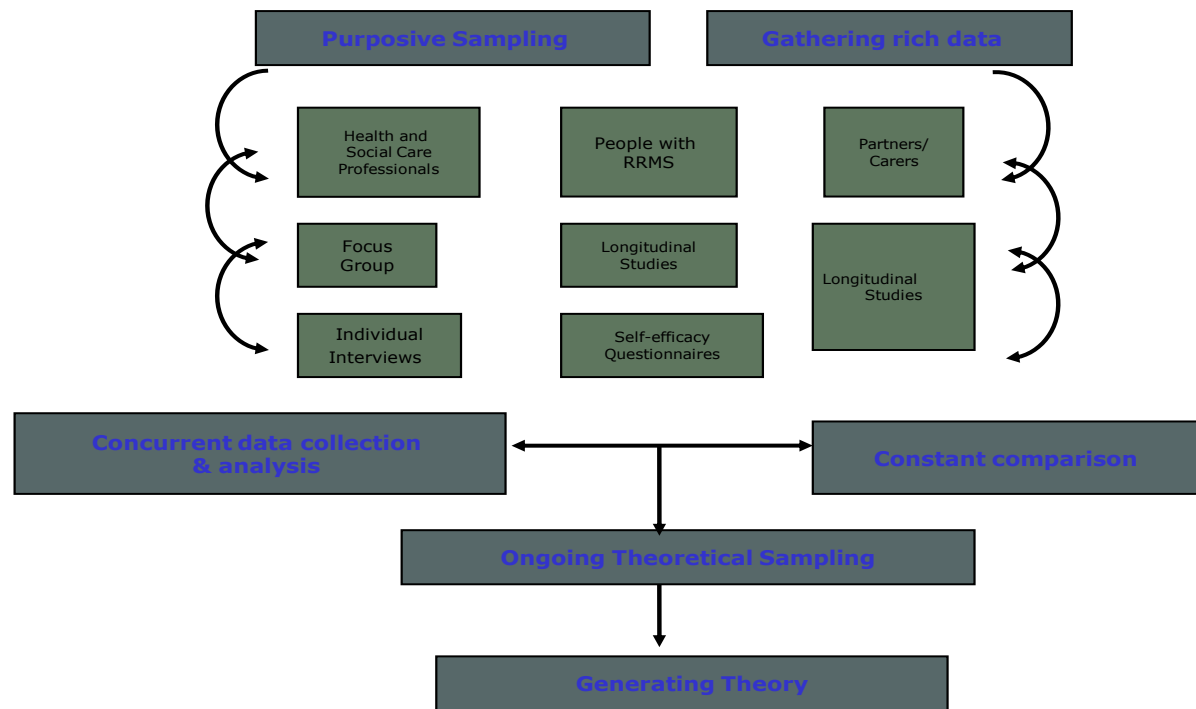
Research Question: How does engagement with self-management and self-efficacy influence the journey of people with RRMS and their formal and informal carers?

The choice of a version of constructivist grounded theory for this study was decided by the research question, together with the consideration of usage of social constructionism, interpretivism, and symbolic interactionism within the applicability and feasibility of the methods in the context of the phenomena of interest (See Figures 3.1 and 3.2). In order to answer the research question a framework was developed to define the boundaries and provide a guideline for collecting data for the research (See Figure 4.1). The research was aimed at generation theory which relates to engagement with self management and self-efficacy of RRMS and the theory was grounded in the data collected from the methods during the study. According to Wiener (2007) "Grounded" simply means grounded in the data and was used initially by Glaser and Strauss (1967) to signal rejection of the conventional approach, whereby existent sociological theory was seen as the beginning of research and imposed upon new data. 'Grounded' was meant by them to mean that new theory was to be generated from new data. By 'theory' they simply meant an explanation of the inter-relationship between and among concepts, in order to present a systematic view of what is going on. The grounded theory method generates the intricate relationship among a wide number of concepts.

Methods used:

Focus Group Interviews were used to allow exploration around a range of perspectives of particular phenomena linked to self-management and self efficacy. Focus groups provided an efficient technique for qualitative data collection, which provide a rich source of information for analysis through abstract concepts being discussed, with the amount and range of data and insights coming from several people at the same time. They are open-ended discussions between the researcher and a group of people (usually between 6-12 people) for the purpose of collecting research data on a predefined set of ideas from a topic guide. They can also serve similar to a brainstorm in triggering/sharing ideas, concepts and for the group to learn from one another in terms of how processes fit together and where their own parts fit within the structure. They provide social spaces in which the participants can co-construct their understanding through discussion, alignment and persuasion. The group members are chosen as they are deemed to be knowledgeable in the areas that are focal to the research. Focus groups allow the researcher to access the attitudes and values of the group while observing the

Figure 4.1: Framework for the Research Process



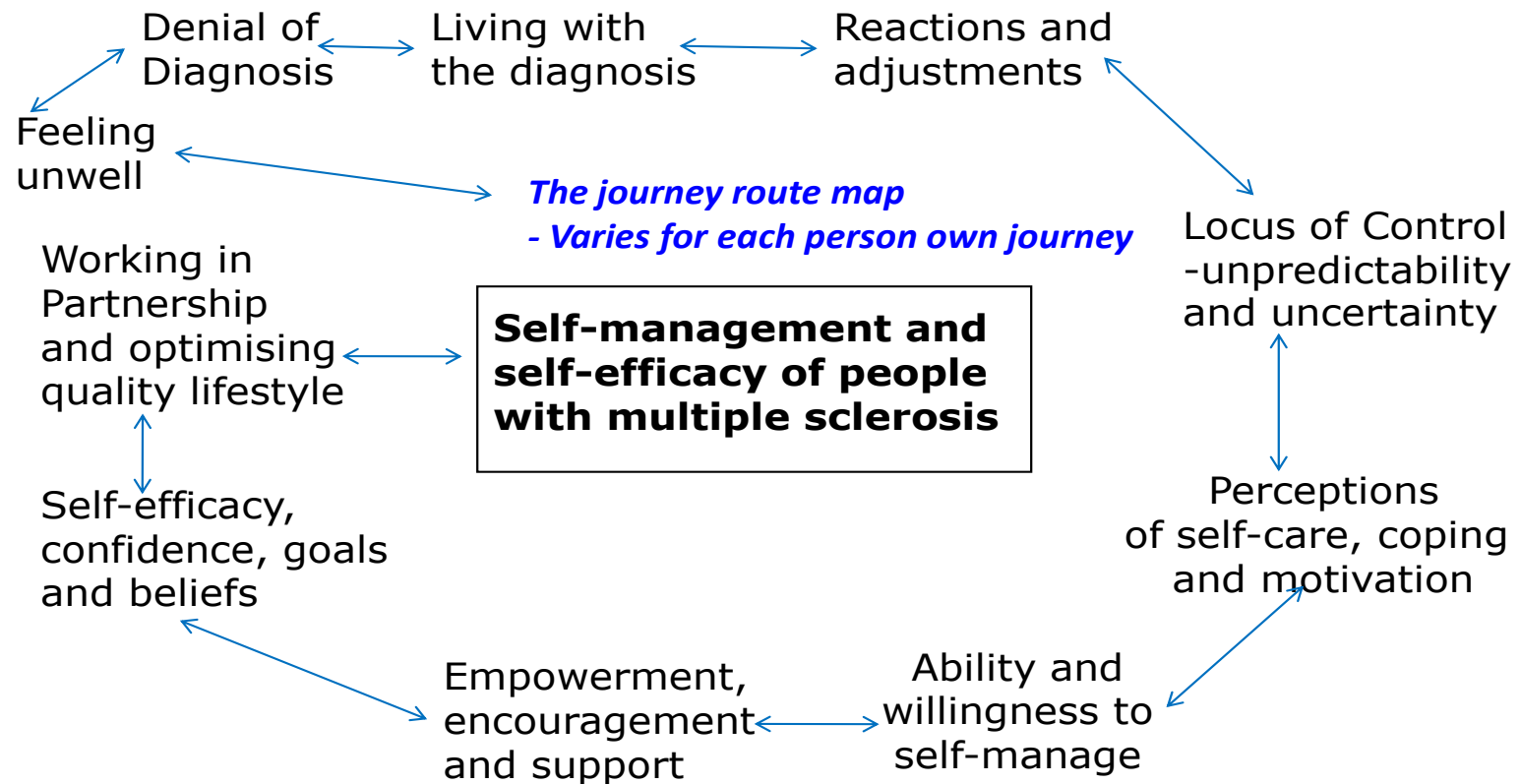
interactions of the participants. They do require good preparation and facilitation to ensure that they run smoothly, that all members have the opportunity to participate and that only one person speaks at a time.

Longitudinal Studies

The case for conducting longitudinal studies was based on the sociological and philosophical viewpoint that reality is experienced in concepts that are constantly changing over time to allow phenomena to develop and to capture any changes that take place (Flick 2009). They allow trust to build up between the researcher and the participants which allows the collection of data around attitudes, beliefs and behaviours which change over time. They can be used to capture information data on development changes across phases or stages of lifestyle and coping with chronic illness. When a trusting relationship is developed between the researcher and the research participants, the participants are more likely to provide detailed, accurate and meaningful information, which can have an immense impact on the quality of the data collected and, ultimately, the quality of the research findings. Glaser & Strauss (1967) maintain that the researcher should return to the field continually in order to test the relevance of ideas and to stimulate further developments. Longitudinal studies permit this approach. The problems can be that people may drop out due to illness or death and they are costly due to the number of interviews and the time it takes to transcribe and analyse the data.

In order to gain individual perspectives on RRMS with its uncertainty and unpredictability with problems encountered on a daily basis such as symptom management, social isolation and coping mechanisms it was important to study the people with RRMS over time. The longitudinal studies over eight months with the people with RRMS and their partners/carers, being interviewed individually through an open-approach using a topic guide to ensure all of the conceptual framework areas would be covered. This was undertaken using a tool developed by the researcher following the literature review which set out the RRMS journey stages (see Figure 4.2 Journey Map). This allowed discussions for the people with RRMS and their partners/carers to explore and relate these areas to their own personal journeys. During interview eight they drew their own personal journey maps which are in Appendix VI.

Figure 4.2 : MS Journey Map – exploring routes



The longitudinal studies required the researcher to spend sufficient time in the research setting to enable her to select, from the mass of data collected, the data which is relevant and representative of the phenomenon being studied. In Grounded Theory research this is closely linked to theoretical sensitivity, where the researcher becomes increasingly aware of the important data as the theory continues to emerge from the data and the themes became increasingly saturated. Ongoing observation also contributes to the development of the researcher's reflexivity as understanding of the participants' experiences developed over time. Also the researcher was able to engage in frequent and extended periods of observation in the participants' own natural environment during the hours she spent with them over each of the eight months. Over this time the participants' and the researchers' constructions mature and become more insightful. These strengthened the researcher's ability to identify important items of data and to develop the themes and emerging theory until saturation was achieved.

Semi-structured Interviews

The decision to use interviews was influenced by the nature of the research question, the aims of the study and the chosen methodologies. Semi-structured qualitative interviews are in-depth open face to face interviews using a topic guide which allows for open discussions around the phenomena being studied. They can resemble everyday conversation for the purpose of collecting and validating data (Chenitz 1986). Semi-structured interviews allow the interviewer to move freely from one topic to another to allow the flow of information around the topics being studied. While also at the same time allowing the participants to introduce areas that they felt were important to them. They do require some degree of control in order to keep them focused but they should not be turned into a rigid question and answer session as much of the depth would be lost as the participant would not feel free to express and share their personal perspectives without interruptions (Flick 2009). The researcher listens and probes as appropriate but does not reveal their own values and experiences. The researchers own values and experiences were recorded in the reflective diary and considered during the analysis stage.

Topic Guides

These are a broad guide to the areas that might be covered within the interviews and focus group which are open-ended and flexible. The topic guides were developed by the researcher based upon the conceptual framework which was constructed using the theoretical perspectives, personal observation and experiences of the researcher and the theoretical position of the research. As the data analysis proceeded, subsequent interview topics were supplemented by issues arising from earlier interviews and Open and Axial Coding of these. Care was taken to avoid too much structure on the interview, otherwise the quality of the data would be affected (Schreiber 2001). The areas were around the phenomenon being researched to set the context and boundaries of the study to allow depth and free discussion. Each topic is introduced by an open ended question and ended by a confrontational question and are answered on the basis of knowledge and personal experience of the interviewee. Different perceptions and experiences shared during the interviews were added to the topic guide for constant comparison with other research participants to densify the properties and dimensions of the categories which were being generated by simultaneous coding.

Self-Efficacy Questionnaire

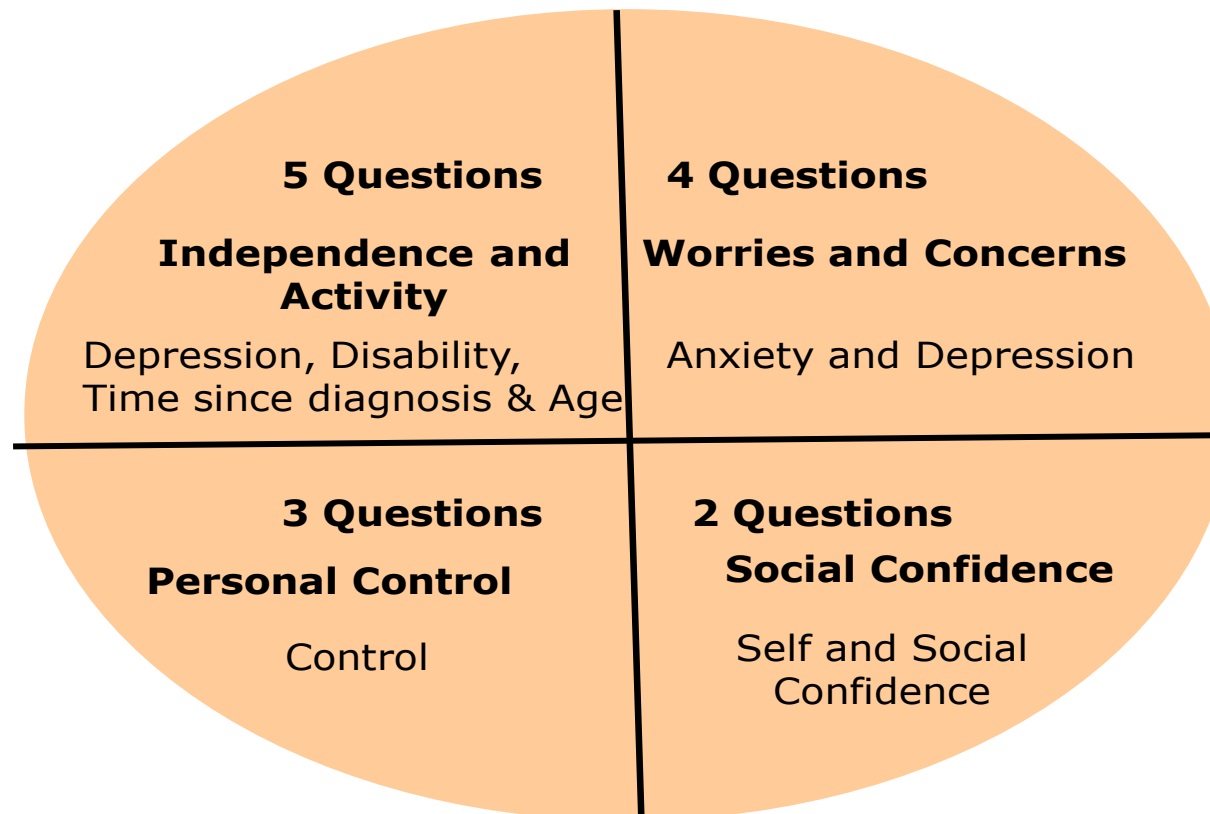
A number of questionnaires were reviewed for potential use and this one was chosen because it was the only one which was user-led involving people with MS directly at each stage of development. It also involved feedback from professionals working directly with people with MS in recognised neurological centres. This questionnaire was developed by Rigby et al. (2003) as a potentially useful tool in the assessment of psychological adjustment and quality-of-life of individuals with MS. The self-efficacy scale was developed over a number of stages involving individuals with MS with open ended patient interviews about how their lives had been affected by MS and through exploring their responses to these difficulties and the impact on their feelings. Initially the researchers piloted a 20 items scale from the discourses they coded describing self-efficacy beliefs. They then randomly presented the statements using a six-point Likert scale ranging from 'Strongly Disagree' to 'Strongly Agree' and used it on a convenience sample of 46 MS patients. Each participant was asked to complete the scale and comment on the relevance and clarity of the 20 items. The items were then reduced to 14 through the consultation process and the 14 item scale was then administered to

142 people with MS and a random sample also completed the questionnaire again eight weeks later in order to assess test-retest reliability.

The scale was reported by Rigby et al. (2003) as demonstrating high internal consistency (Cronbach's $\alpha = 0.81$) and test-retest reliability ($r=0.81$, $P<0.001$) and acceptable validity. The scale has shown sensitivity to detect changes following brief psychological therapeutic intervention, with an effect of 0.502. It has been demonstrated to have good psychometric properties in terms of reliability and has the potential to detect change. It is also stated to be highly valid in its relevance to individuals with MS, although its validity as a measure of self-efficacy beliefs may prove moderate. Rigby et al. state it is a useful tool for both clinical and research assessments of psychological adjustment. They also recommended the use of the questionnaire over a longitudinal study.

In this research the self-efficacy questionnaire was used as a qualitative research tool for secondary data collection, to look at the changes over the eight month period in relation to how the person with MS was feeling on the day of the meeting session. It enhanced the data collection by allowing augmentation of the primary data obtained from the semi-structured interviews. There were wide variations in how each question was answered over the eight months by each of the six people with RRMS and they appeared to relate to how they were feeling on the day and what had happened since our previous session in terms of their MS. There was a fluctuation in self-management behaviours in line with low self-efficacy and more complete higher quality information shared when the self-efficacy levels were higher. The effects were also related to their current state in terms of depression, anxiety, stress and reduced sense of well-being resulting in lower levels of confidence and perceptions of reduced capabilities. The four dimensions into which the question areas measure are Independence and Activity; Worries and Concerns; Personal Control; and Social Confidence (see Figure 4.3). A summary of the data analysis and results of this questionnaire are presented in Chapter five to demonstrate the fluctuations over time and a more detailed analysis is available in Appendix V.

Figure 4.3: Question Areas of Self-Efficacy



Adapted from S A Rigby et al, 2003

Triangulation

A mixed method approach to data collection was chosen because it was felt that they would corroborate each other and produce richer data than a single approach. This required the researcher to use different methodological approaches and methods to collect data in an attempt to strengthen the theory as it emerged. In this way different sources of data can be used to further explore, explain and support themes as they develop during data analysis. Multiple data sources helped the researcher to become increasingly familiar with the setting and the participants and further strengthened theoretical sensitivity. Using a mixed method approach in this way added depth to this research and enabled the researcher to explore the multiple themes of the theory presented later in this thesis. This would allow examination of the varied dimensions and complexities of self-management and self-efficacy which people with RRMS engage in. The self-efficacy qualitative questionnaire enhanced the data collection in comparing the dimensions and what supported and differed with the level of self-management at particular times throughout the longitudinal studies.

The decision to use a mixed methods approach was also influenced by conflicting literature about the trustworthiness and rigour of using a single approach (Benoliel 1996; Charmaz 2000; Morse 2001). Triangulation of methods was achieved by using focus group and semi-structured interviews, longitudinal studies and a qualitative self-efficacy questionnaire. Three different groups of participants (people with RRMS, their partners/carers and professionals involved in MS care) provided triangulation of sources. Triangulation of sites occurred when data was collected within the natural environments of the family homes, rehabilitation centres, GP surgeries and acute hospital settings.

Personal and Reflective Diaries

Personal and reflective diaries were completed by the researcher, of events throughout the study and are being used as decision and audit trails to contribute to the rigour of the research. The researcher's personal views and responses while collecting data that might influence the findings were also recorded. These findings were coded in the same way as all the research findings and used to justify decisions made and reasons for any changes that were made during the study. Detailed entries were made after each visit to research participants in which

issues relating to the research were documented throughout the research. These handwritten and typed entries were treated as confidential material because they recorded and commented on some sensitive issues to both the researcher and the research participants (De Laine 2000). These were treated as data and therefore the secure storage of these notes was treated as serious an ethical issue as the secure storage of other forms of data. For this reason, the personal diary was kept in a locked safe and the reflective diary was password protected on my computer. These were maintained throughout this research and were used to record:

- preconceived ideas about the research, the research settings and the people with RRMS experiences
- personal beliefs and opinions of different situations
- the progress of the research, including any problems encountered, decisions made and actions taken
- commentary on relationships and social interaction with participants
- commentary on non-verbal communications and the behaviours observed during the sessions
- things said and done after recording had started or stopped
- emotions experienced and reasons where possible to determine
- feelings when listening to the tapes and being able to visualise the session and how things were progressing or being made more positive than they were
- initial ideas about emerging themes and the developing theory
- notes about relevant literature and how this might contribute to elements of the emerging theory.

Reflection on journal entries helped with identifying my personal knowledge and identification of any assumptions or biases that may influence the experiences of the research participants. During data analysis extracts from these diaries were inserted as memos within the computer software. This process aided theoretical thinking, helped to ensure continued reflexivity and guided the development of interview schedules for subsequent interviews. These field notes were read and re-read on multiple occasions and frequently contributed much to clarifying the researcher's thinking and the development of the theory generation.

Research Phases:

Phase 1: Professionals' Focus Group and Individual Interviews

The researcher decided to start the project with the professionals in order to enhance her local knowledge and understanding prior to working with the people with MS and their partners/carers. The first semi-structured interviews were individually with the two GPs who generously gave their time and informally discussed how the topic areas related to their own experiences and practices. For each of the interviews including the focus group the non-verbal symbols were also observed and recorded. Immediately after each interview the researcher recorded her experience including the non-verbal communication in her reflective diary. Individual interviews were also held with the Specialist Continence Nurse, Community Matrons/District Nurses, Consultant Neurologist and MS Specialist Nurse; Rehabilitation Consultant and MS Team Leader Physiotherapist; and Senior Social Worker and Welfare Benefits Officer from Social Services.

The focus group was selected in a purposeful way to orientate the researcher to the contextual issues and services that were available for people with RRMS and to allow open discussion and insights into the areas encountered by the multidisciplinary team. One of the focus group members led on the topic areas and as she led on the previous meetings to date there were no hierarchical pressures. There were nine professionals in total including the researcher and a mix of physiotherapists and physiotherapy assistants, community matrons, occupational and speech and language therapists. There was some anxiety in the room with regards to the topic areas and what they would be asked to discuss. The researcher introduced the focus group and set the ground rules, explained her position and who was going to lead on the topic areas. All were asked to ensure that they participated to make sure their voices were heard and the researcher would encourage people to join in. The researcher started by asking everyone to introduce themselves and to explain their role and responsibilities with people with MS and their partners/carers. She then asked them to state at which time they became involved in the MS journey and how they generally received their referrals and from whom.

The lead person opened the topic discussion by reading the DH definition of Self Management and inviting the group to comment on the content, the words used

and the applicability to people with MS. The group quickly relaxed and got into the topic areas and were all speaking fairly freely and speaking clearly one at a time. The group stated that they enjoyed sharing their experience and learning from each other and exploring ways in which they could work together better and to improve the MS service provision. The researcher ensured that all the participants offered their opinions and did not just drift into chatter or just share endless anecdotes and the group leader kept them on track with the topic areas. Many important areas were covered in the focus group and the individual interviews and these will be applied and discussed in detail over the next four chapters of this thesis.

Phase 2 Longitudinal Studies were used based on the sociological and philosophical viewpoint that reality is experienced in concepts that are constantly changing and in getting to know people over a period of time they are more trusting and willing to share changes and feelings. The discussions were undertaken over an 8 month period exploring how RRMS affects their lives, to tell their story, make connection, plan actions and to share their journey in describing what has helped them along the way and how they see their future. The partners /carers were seen separately which they stated proved to be more beneficial to them in feeling they could be more open and honest during the discussions. The researcher was actively interacting with the people with RRMS and their partners/carers to see things from their point of view, and in their natural context. The self-efficacy questionnaire was completed by the person with RRMS prior to starting each interview and was based upon how they were feeling on that particular day.

The longitudinal studies with the six people with RRMS and their partners/carers over the eight month period allowed for the recording and documentation of the changes over the time period. As the time passed the participants' and the researcher's constructions matured and became more insightful. Observation of the non-verbal communication and the researcher's reflections were also recorded during and immediately after each of the eight sessions. The strength of longitudinal studies is being able to document changes of view or action through repeated collection cycles, where the initial state of a process of change can be recorded without any influence from its final state – cannot therefore be fully

realised (Flick 2009). The RRMS trajectory is not a linear process but with fluctuations and unpredictability using a longitudinal approach allows the researcher to explore this process further. The changes, unpredictability, uncertainty and adaptability did change repeatedly over the eight months along with the perceptions of the present and the future. These were also reflected in the Self-Efficacy Questionnaire which was completed by the person with RRMS prior to our discussions at each session. There were asked to complete the questionnaire based on how they were feeling on that day and to honestly reflect on each question and to score it accordingly.

Phase 3 - Data generation, analysis and evaluation

Constructivist grounded theory studies are reflexive in design, repositioning the researcher from being a distant expert (Charmaz 2000) to being a data collector through semi-structured interviews with participants in the generation of data. The application of the four methodologies of social constructionism, interpretivism, symbolic interactionism and grounded theory; were utilised in reviewing and comparing the multiple realities of meanings, perceptions and experiences applied to making sense and order of the data generated. Researchers reconstruct data into a theory that they themselves must own, while simultaneously grounding it through the use of active codes (Charmaz 2006) reflective of participants' words. Data in this project was collected across the three groups involved in the research study (Figure 4.4) and was co-constructed in the findings in Chapter six, seven and eight.

The topic guides for the focus group and interviews and self-efficacy questionnaire can be found in Appendix III and V. The data analysis will be discussed in Chapter five of this thesis.

Figure 4.4: Research Data Collection



Conclusions

The research study used qualitative methods of reflective and personal diaries, individual interviews, focus group, longitudinal studies and self-efficacy questionnaires for data collection. These are all consistent with the methodologies as set out in Chapter three. Both phases one and two have collected vast amounts of rich data which were all electronically recorded and transcribed verbatim and have been analysed into the three separate groups of the people with RRMS; their partners/carers; and the health and social care professionals. The data analysis and application of the theoretical frameworks will be further explained and developed throughout the next four chapters of this thesis.

Chapter Five – Data Analysis

Introduction

This chapter sets out the theory of data analysis and how this has been applied to interpreting the research transcripts, questionnaires, reflective and personal diaries, which were discussed in Chapter four. Seeking understanding is the aim of qualitative research (Schwandt 1999) and interpretation is about making sense of what has been learned through the research process. The meaning of interpretation is to explicate, grasp, get, catch, or comprehend the meaning of something (Schwandt 1999). The process through which this is undertaken is data generation and analysis. Denzin (1994) referred to this as the making sense of the 'art of interpretation' and the practice of art is translating what has been learned into a body of textual work that communicates these understandings to the reader. Data is grounded in the actual experiences of the research participants as heard by the researcher and told through reflection and interpretation of the research process. Denzin (2000) stated that qualitative interpretations are constructed and created when the researcher becomes the listening conduit through which such voices can be heard. The researcher then becomes the conduit teller, through which interpretation as a process of learning, can then be applied to data analysis using the methodologies and sharing the findings from the research process through the voice of the participants.

Throughout the thesis attempts have been made to expose the main approaches adopted at different stages of the study to enhance the reflexivity and rigour of the research study. In grounded theory there are two major approaches that are integral to the data analysis process and these are making constant comparisons and asking further theoretical questions. A great deal of time was spent carrying out and becoming immersed in the data and analysis processes which were not confined to discrete explicit activities. Sometimes things would come to me in an implicit way, for instance, when I was doing housework or sleeping and I was reminded of a conversation or something I read in transcript and I would immediately write these thoughts down. These were things that were playing on my mind or that I was struggling with the idea and how to put it context. I also used the tools of grounded theory which helped in a more explicit way. The findings of the research will be shared in Chapters six to eight. This chapter will explain the

way that the data analysis was undertaken using multiple methodologies and how the central theme and the major themes emerged to provide the eventual lead-up to theory.

The research study is attempting to understand the meaning or nature of experience of people living with RRMS and finding out what people are doing, thinking and engaging with in terms of self-management and self-efficacy. Qualitative research and data generation/analysis are ways of obtaining intricate details about feelings, thought processes and emotions and the impact these have on social reality. There are processes that the research goes through to interpret and organise the data using the multiple methodologies. The research process within the interpretivism qualitative paradigm looks at the ways in which people understand the nature of their social world and their participation in social and cultural life; social constructionism brings the engagement with reality through meaning and knowledge; and symbolic interactionism the way people socially interact to bring meanings and actions to understand how and why things are that way within their own natural context (see Figure 3.1). Through the grounded theory methodology people make sense and order of their social world by exploring the way people engage and interact with the world to create understanding and social actions. Throughout the data analysis these methodologies interplayed and complimented each other to support the creation of substantive theory.

These are examples of interpretivism from this research was around the interpretation of Consultant Neurologists as experts in MS. Three of the people with RRMS described their Consultant as an expert with knowledge and understanding, who discussed issues in the best interest of the patient through joint decision-making, choice and partnership working.

“Well I think I am very independent and if I am advised to do anything I will discuss it with the professionals and I would do it but if I do not agree with it then I would tell them that and I would not do it. Erm like when I see the Consultant now at the RVI for my waterworks he wanted me to have something on to control it and I thought no I do not really want that and I told him that. I have spoken to people and they say it is fine but something inside is saying no and I am fighting it really. I see that as being in control and I will resist it until I feel that I really need what is being suggested. It might be stupid because it might work out to be fantastic but I keep thinking it is worse having to have self-catheterisation and things like that, it is another step down on my independence. I did discuss it with him but I just did not fancy having that done and he said he would leave it for now and review it again later. I know he is the

knowledgeable expert but I will only do things when I am ready and feel that it is needed". **Mary, MS 4, Interview 3.**

"My Consultant is really helpful and involves us in the conversations and wants us to make the decisions with his support. He started off saying I have 2 drugs for you which I think will help and you need to decide what you want to have. It was good the way the Consultant threw it back at us and wanted us to have the choice it was very good. He had the MRI scan on the computer screen in his office which showed both results from the last MRI scan and the one which I had in March. He said as you can see there is a lot of difference there are a lot of lesions and brain activity difference from what the last time was. He obviously knew what he was looking for but the colours on the screen were totally different from the one that was done previously in September last year. That was just before I became unwell with the build up of the antibodies and stopping my treatments". **Amy, MS 1, Interview 3.**

"My Consultant has always been okay and he tries to be helpful through using his knowledge and expertise. But if he says something that I do not know about or I am unsure about I feel confident enough to ask him. The professionals do encourage me to be involved, although I do have very limited time with the Consultant but he does ask me if I have questions and I will ask. I do feel I am in empowered and in control with my appointments and time with the healthcare professionals". **Ian, MS 5, Interview 2.**

Two people with RRMS described their Consultants as being paternalistic, talking down to people and not listening to them, not sharing experiences of the thousand of people these see with MS and having only gained their knowledge through reading books; and People with MS being the experts of their own condition.

"Once you have got the diagnosis there is not much they can do because you go and see the consultant every six months and all he does is to write stuff down. He does not do anything and he only examined me once when I said that I am getting really bad pains in my eyes and dizziness and that and I can hardly sit down and it is happening all of the time and that now. I said that every few days it is happening *erm* he examined my eyes and said that I had damaged the nerve in the back of your right eye and there is nothing we can do about it. He said it just like that and that was it. He just talks down to you and treats you as if you are stupid. He did not even tell me that he thought it was MS and I only found out by reading my notes in the GP surgery. I just feel so helpless, uncertain and insecure and he does nothing for me. I am the expert in my MS and he only knows things from reading books but he thinks he is an expert in MS". **Michelle, MS 2, Interview 2**

"The MS nurses are good and I find them better than the consultant they tell you more and they seem to be more knowledgeable, or more forthcoming with their knowledge than the consultant. The consultants seem to think the knowledge they have got is theirs and that they should not share it with the patients, you know. They see thousands of people with MS but are not prepared to discuss or share those experiences. That does not empower the patients but the MS nurses want to and are prepared to do that. I cannot fault the MS nurses if they can not answer they would go and find out for you. I mean it is alright for me, consultants there alright if you want something prescribed, and they have got to say yes or no. But apart from that, they are useless, they have loads of knowledge but they will not share it because they feel information is power and they talk down to you. I usually get to see him for about five minutes and that is him talking and asking me questions. He does let me ask questions, and he does give me time because I think he has too but he does it reluctantly. I feel the visit is unless it is like he is talking to a seven year old child". **David, MS 6, Interview 4.**

An example of symbolic interactionism, through interacting with other people, in this research were around the differing ways in which people with RRMS viewed the meanings and experiences of self-help groups in their social world such as the drop-in centre. Some viewed it as a good place for people to meet, learn from each other and share their experiences through socialising. Others described it as a “pity-me club” where people weekly told their MS stories, moaned about the lack of support and finance to help them cope with their condition and never really moved forward in acceptance and coping.

“At the drop-in we are all learning from each other all of the time and I really enjoy this. We discuss income benefits and treatments and make sure we are all aware of what is happening, to make sure we are getting what we are entitled to. Sometimes when I am having a smoke with them we do talk a lot and that is in a smaller group and it is good. I look forward to going there as I have met people I probably would never have spoken to if it was not for MS”. **Michelle, MS 2, Interview 3**

“We went to the Drop-in Centre last Tuesday and we saw the ladies that we normally see on a Thursday at the exercise class, but I thought because they dwelled so much on the subject of MS. They talked how they first got the illness in the first place and through their MS journey – I really do not want to hear this. It was like a pity-me club with no looking forward to the future. You know I wanted to go away from this because I had been through it and so had all of them, but it upset me too much it was well this is what happened to me. I thought I really do not want to hear this because I had been through all of this, I remember it from the very first day when I knew something was wrong, and so I do not need to be thinking about that as it was some time ago now. I had to prove to myself that I was not like them so I went home and drove my car for the first time in six months”. **Amy, MS 1, Interview 4**

The research processes in grounded theory consist of conceptualising and reducing the data, elaborating categories in terms of their properties and dimensions, and relating through a series of prepositional statements (Strauss & Corbin 1998). Conceptualising, reducing, elaborating, and relating often are referred to as coding (Charmaz 1983, 1995; Miles & Huberman 1994). In Grounded Theory data collection, analysis and eventual theory stand in close relationship with one another (Strauss & Corbin 1998).

According to Patton (1990) qualitative evaluation allows creativity of researchers to draw both critical and creative thinking from the research which is both the science and the art of the analysis. The science is the sense of maintaining of rigour and by the grounding analysis of data. The creativity manifests itself in the ability of researchers to aptly name categories or themes (high level concepts used to reduce and combine data), ask stimulating questions of the data, making comparisons between the categories, and extracting an innovative, integrated, realistic scheme from masses of unorganised raw data (Patton 1990). Patton

stated that the analysis is the interplay between researchers and data. The researcher scrutinises the data in an attempt to understand what is being expressed in the raw data (Strauss & Corbin 2008). This scrutiny is about focusing on the data through asking theoretical questions, synthesizing the data through the properties and dimensions and not taking anything for granted (see Appendix IV for an example of this process). Also included is the coding for emerging concepts (from the data) which is done by close scrutiny and with the intention of developing core categories.

In grounded theory this is undertaken through theoretical sensitivity, theoretical sampling, constant comparison analysis, coding and categorising the data. The tools utilised in this research included open, axial and selective coding, data synthesising frameworks, memos, analysis maps, mind maps, theoretical sensitivity and co-construction of meaning with the research participants. These are described in this chapter in more detail in relation to how they were used in this study. Seeking understanding is the aim of qualitative research and interpretation is about making sense of what has been learned through the research process. Reflexivity makes the researcher more self-conscious about what she is doing in utilising the model of knowledge, to grasp where the knowledge comes from through professional learning, and is used at every step throughout the research process. It is about questioning your own assumptions and values in the process of the research and justifying your research design and outcomes through your contribution to knowledge. Rigour has been attended to through reflexivity and by providing explanations to the reader about decisions made and the directions taken throughout the research study.

Theoretical sensitivity

The qualitative interpretivism paradigm focuses on the search for meaning and understanding to build innovative theory. Theoretical sensitivity is one way of guarding against the potential biases that could threaten the rigour of a study. It is the ability of the researcher to think inductively and move from the particular (the data) to the abstract or general (Schreiber 2001). This can help to curb any potential bias from the researcher's background experience and diminish the risk of compromising the study through premature closure in favour of the researcher's preconceived ideas. The goal being to understand the shared social experiences

from the research participants' perspectives, and to allow generation of the theory which is truly grounded in the data. In discussing their personal journey with the people with RRMS and their partners/carers I used a journey tool which I developed from my understanding of the steps and stages of the MS journey based upon the literature reviewed (see Figure 4.2). This was shared with the participants in order to gain their own perspective and social experiences of their own personal trajectory. Upon the explanation of the terminology used I found some of them were trying to use the same concepts and had to keep reminding them to share their journey in their own words and meanings. I was aware of this in terms of rigour and the interactional element of the research relationship in the co-construction of knowledge and meaning that is required in qualitative research. It is important that the information and meaning comes from the research participants through their own interpretation, interactionism and social construction.

Theoretical sampling

Close inspection of the data extends the theory through the theoretical sampling process. This means that rather than predetermining the characteristics and size of the sample, the developing theory directs the researcher to planning the next visits with the aim being to maximise opportunities to compare events, incidents and happenings Strauss & Corbin (1998). Theoretical sampling is the process of data collection for generating theory through collecting the data, transcribing, coding and analysing it and then deciding what data to collect next. The topic areas were planned for the next meetings and decisions made on where to best find the information, in order to develop the theory as it emerged. This process of data collection is "controlled" by the emerging theory Glaser (1978). The process involved the coding strategies with breaking down the data from my research activities into distinct units of meaning which were labelled as nodes to generate concepts. These concepts were initially clustered into descriptive categories and subcategories through axial coding. Return visits to the people with RRMS and their partners/carers focused on asking further theoretical questions which were aimed at developing, densifying and saturating the categories through consistency and flexibility. They were then re-evaluated for their interrelationships and through a series of analytical steps and were gradually subsumed into higher order categories, with one central theme and three major themes which indicated the

emergent theory. Constant comparison was an ongoing feature of the process with the emerging themes being sorted on the basis of similarities and differences.

Data analysis and evaluation

According to Sword (1999) within a qualitative study, the researcher's curiosity, relationship with participants and conceptual lenses through data are gathered and interpreted which have significant bearings on the research. It is through this interactive and transformational process that the researcher listened and learned about and interpreted the telling of the life experiences which were shared with her through the theory generation process. This enabled the research participants to speak in voices that were clearly understood and represented. The theory generated from this research contributed to the knowledge of how engagement with self-management and self-efficacy influences people with RRMS and their formal/informal carers by providing a common language through which they all came together to discuss and find solutions to the problems they all have identified. Guba & Lincoln (1989) suggest construction of the research is sharing the views of the participants. They share the notion that the researcher and the researched during the process of the project construct knowledge.

"Constructions are, quite literally, created realities. They do not exist outside of the persons who create and hold them; they are not part of some "objective" world that exists apart from their constructors" Guba & Lincoln (1989: 143)

The first step was to listen to the recording of the interview again and to start taking notes of any areas for review or further exploration during the next interview. All interviews were transcribed verbatim and the key issues clarified with the research participants during the next interview. Qualitative data analysis tools were reviewed and NVivo 7 was chosen by the researcher as the most appropriate tool for the three stages of coding used within Grounded Theory. The transcriptions were then entered into NVivo 7 Computerised Qualitative Data Management Programme (CQDMP) for microanalysis which is an important step in the theory development. The interviews were then read again to reinforce and to review the context under which things were explained and shared. The thinking about what is being said is what brings the researcher into the analysis process and drives the qualitative analysis. Then line by line analysis is undertaken by coding the data and uncovering new concepts and looking for relationships through asking questions and making constant comparisons. When the incidents

were found to be similar they were put under the same conceptual code and new areas were given a new code to build up the general properties, dimensions and bring variations.

Constant comparative analysis

Constant comparison was an integral component of the data analysis strategy used during this research. It was described by Glaser & Strauss (1967) as an inductive process where the researcher compares each new item of data to the data previously collected. This involved taking one piece of data and comparing it with all the others which were similar or different in order to develop conceptualisation of the possible relationships between the various pieces of data. This was to generate knowledge about the common patterns and themes across the experiences that were shared with the researcher. Constant comparison was central to the rigorous development of theory and began as soon as the first item of data was collected and continued, throughout the research, until the final report was completed. I moved back and forth between the data, the developing themes /categories and generating theory which at times caused tensions and decisions had to be made to find the best fit for the data. This was difficult at times due to the time period between the interviews, transcribing and coding. The developing categories guided future data collection, theoretical saturation and the demonstration of scientific rigour by ensuring a robust theory with no theoretical weaknesses.

Coding and categorising the data

Coding is the core process in the grounded theory and it is through this that the conceptual abstraction of the raw data and developing them in terms of properties and dimensions for reintegration as theory takes place. The essential relationship between data and theory is a conceptual code. The concepts are the words that stand for the ideas contained within the data and are interpretations of its analysis. Coding is described by Strauss & Corbin (1998) as fracturing the data, then using concepts through conceptual ordering, to see the underlying description and pattern of a set of indicators within the data as a theory that explains what is happening to the data. Thematic analysis is a method of identifying, analysing and reporting patterns (themes) within the data. Incidents are then analysed and coded, using the constant comparison method, to generate theoretical categories

including their properties (characteristics that define and describe concepts) and dimensions (give specificity and range to the concepts). The goal is to offer a conceptual explanation of a latent pattern of behaviour (an issue or concern) that holds significance within the social setting of the RRMS journey. It must explain, not merely describe, what is happening in the social setting. The categories emerge from close engagement with the data and are subject to constant comparison to investigate differing perceptions. Glaser & Strauss (1967) described categories as 'conceptual elements of a theory'. According to Strauss & Corbin (1998) a well developed theory is one in which the concepts are defined according to their specific properties and dimensions. Dey (2007) thought of categories as forming the theoretical bones of the analysis, which are later fleshed out by identifying and analysing in detail their various properties and relations. This was a good way of describing it and helped in the project management of the data.

Coding is not simply part of the data analysis; it is the "fundamental analytical process used by the researcher" (Corbin & Strauss, 1990). It is what transports the researcher and their data from transcript to theory. There are three phases to the coding (open, axial and selective) which can be carried out concurrently but each phase requiring different interventions on the part of the researcher (An example of the coding, memo, the theme development and further synthesising framework can be found in Appendix IV).

Open Coding allowed the data to be conceptualised and broken down into discrete parts, in order to conceptualise and categorise them with properties and dimensional ranges. The data was processed systematically using a constant comparative method of analysis with repeated comparisons of the information within the transcripts. It was about asking questions of the data and focusing on emergent patterns of the phenomena among the incidents by generating codes into concepts, which fit into the area of study. Grounded theory is about letting the concepts emerge from the data and conceptualising the concepts through the emerging patterns that explain what is happening in the data. Constant comparison protects against over-interpretation of the data and finding connection where there are none. Initially this did feel a little bit awkward due to uncertainty and probably taking too much data to try and demonstrate a fit with the concepts

but as confidence grew there was a pattern that could be seen emerging from the analysis.

Open Coding was undertaken with line-by-line coding of the data and comparing incidents to each other in the data and coding it in such a way to verify and saturate categories. The initial coding involves close scrutiny with the data. Data was broken down into discrete incidents, ideas, events, and acts and then given a name that was represented by the categories for these (Strauss & Corbin 1998).

The aim of open coding is to begin the unrestricted labelling of all data and to assign representational and conceptual codes to each and every incident highlighted within the data. As the process moves forward, iterative reflection of that already coded is considered with new data. This ensured that the relevance by generating codes with emergent fit within the area being studied and building the steps to theory building. The researcher coded for as many concepts as fit successive, different incidents with new concepts emerging and new incidents fitting into existing categories and subcategories. During the open coding there were 81 nodes for People with RRMS, 65 for the partners/carers and 44 for the professional carers. In conceptualising the data it enabled the reduction of large amounts of data to smaller, more manageable pieces of data.

Theoretical memos and diagrams

Theoretical memos and diagrams are used to monitor and stimulate coding, and as a basis for theory integration and ultimately generation. Memos were used to help to look at areas of uncertainty and to highlight areas that were found within the codes and for the best way of capturing the data. This process usually contains the products of analysis or directions for the analysis (Strauss & Corbin 1998). For example, one of my research participants who has RRMS is also a Medical Doctor and the difficulty in coding was where to put the concepts on her thoughts as a person with MS and where to code the concepts of her professional opinions. This difficulty arose in trying to keep the data from the three groups separate, to allow for clear differences between them. This helped in getting my conceptual thought in place while coding and analysing and was also helping with the theoretical sensitivity. The researcher remained open to exploring the areas from the three groups different perspectives, by allowing the concerns of those

actively engaged, to guide the emergence of the core issues. The purpose here of constant comparison is to see if the data supports and continues to support the emerging categories. Strauss & Corbin (1998) state that memos serve the dual purpose of keeping the research grounded and maintaining the awareness for the researcher.

Memos and diagrams were used throughout the research process and were seen as important documents in terms of my research progress, thoughts, feelings and the directions of my research. The memos and diagrams were useful in the development of the theory through reflection on the logic and reasoning around some of the early ideas and how they developed over the time of the project. They were also useful for augmenting data with analytical ideas to reflect on and understand the relationship between and among emerging categories/themes. They also helped in pulling the concepts together for the analytical maps that were used to further explore the categories of the three groups of research participants.

Axial Coding helped to identify central phenomenon, explore causal conditions, specify strategies, and helped to identify the context and intervening conditions and the outcomes of the strategies (Strauss & Corbin 1998). Axial coding identifies relationships between open codes, for the purpose of developing theme codes. Central and major theme codes emerged as aggregates of the most closely interrelated (or overlapping) open codes for which supporting evidence was strong (Strauss, 1987; Strauss & Corbin, 1990). It was used to bring the data back together using a linking technique after it has been broken down and analysed by the researcher and brings them back at a conceptual level. It brought the relating concepts and categories together and it goes hand in hand with the open coding. As I was working with the data I was automatically making connections that came from the data. The same types of questions were asked of the data making constant and theoretical comparisons to add depth and structure and to get the best fit within the categories and subcategories. It is a cyclical process of data analysis which actively uses the spoken words of the research participants to ensure they are grounded in the data.

Diagrams were used here to describe the relationships between the categories and sub-categories and how they related to other categories in terms of

crosscutting and linking. Analysis and mind maps also helped determine the linking categories and the depth of theory which was evolving from each of the categories and how they linked across the three groups of research participants (see Appendix IV for a sample of these maps). This is a way of asking the questions of who, when, where, why, how and with what consequences which helped to build up the structure and process and set the stage and the actions of what was happening across the three groups and look at the connections. The building up of the picture helped to set up the theory and the central and major themes of the research. Through axial coding the 81 nodes for people with RRMS were reduced to 6 Categories; the partners/carers 65 nodes to 6 Categories and the Professional Carers 44 nodes to 5 Categories.

Selective Coding involved the integration, refining and selection of the categories along dimensional level from the axial coding into conditional propositions and theories. The relationship to other categories was made apparent, and validated with the integration being part of an ongoing process with interaction between the data and the researcher. In this way a theoretical framework of interrelated concepts was developed showing posited relationships between the central and major themes. Coding is a cyclical process: shifting from open to axial and then selective coding and, at times simultaneously coding at several levels. According to Strauss & Corbin (1998) it is not until the central and major categories are finally integrated to form a larger theoretical scheme that the research findings take the form of theory. There were analytical tools and interactional phenomenon that supported these processes and have been discussed in more detail in relation to this study within this chapter.

Through integration of the categories, using constant comparative analysis with the data, persistent questioning and analytical thinking, from the three groupings theory was been generated. This revealed a central explanatory concept and the central theme was generated as “The Roller Coaster of RRMS: A turbulent passage in reality” (see Figure 5.1). Once the central category was identified, the researcher concentrated on the remaining categories and the integration of the theory with the categories and subcategories.

**Figure 5.1: The roller coaster of RRMS:
a turbulent passage of reality**



**Figure 5.2 MS Journey Map with themes– the roller coaster of RRMS:
A turbulent passage of reality**

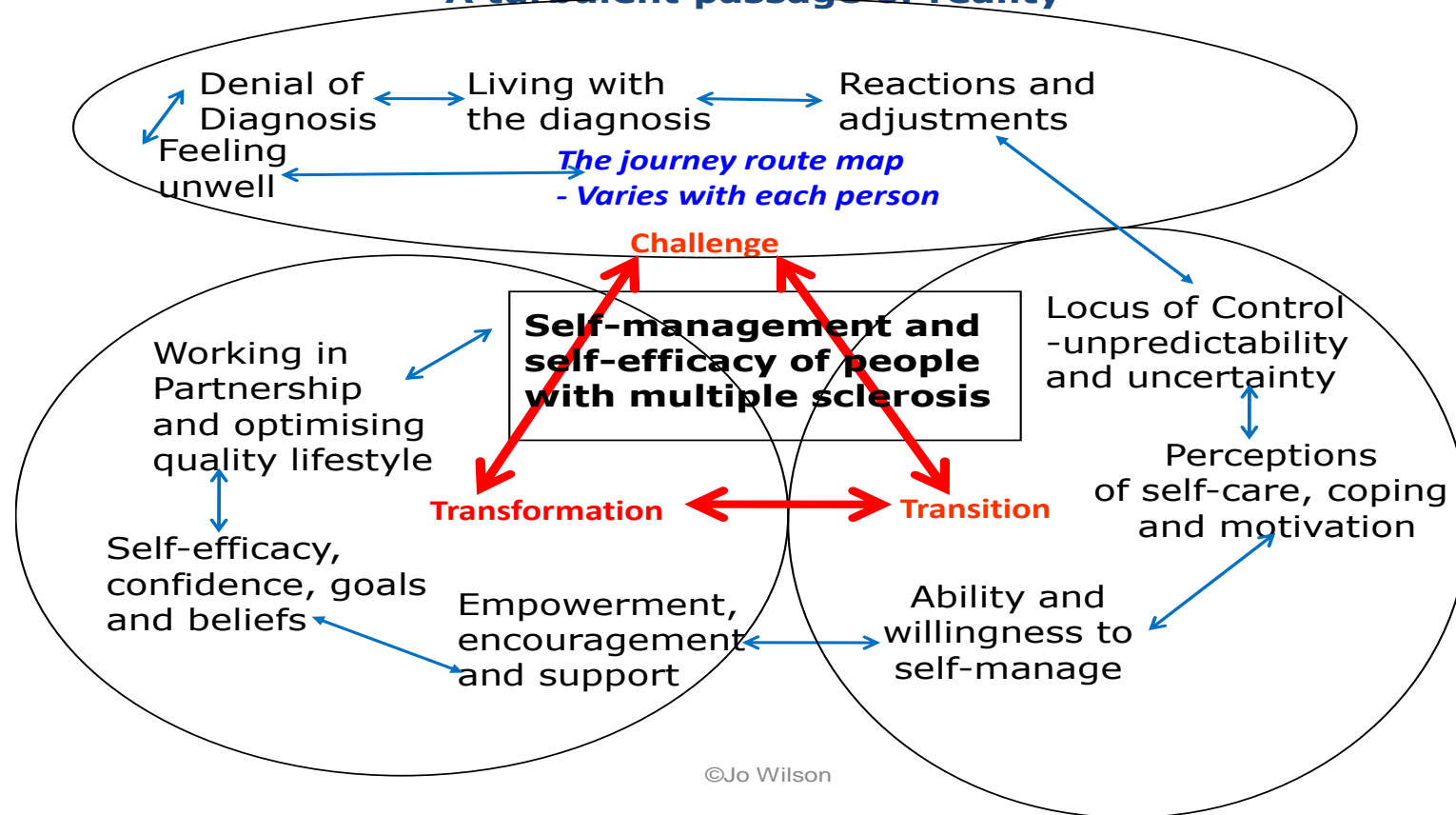
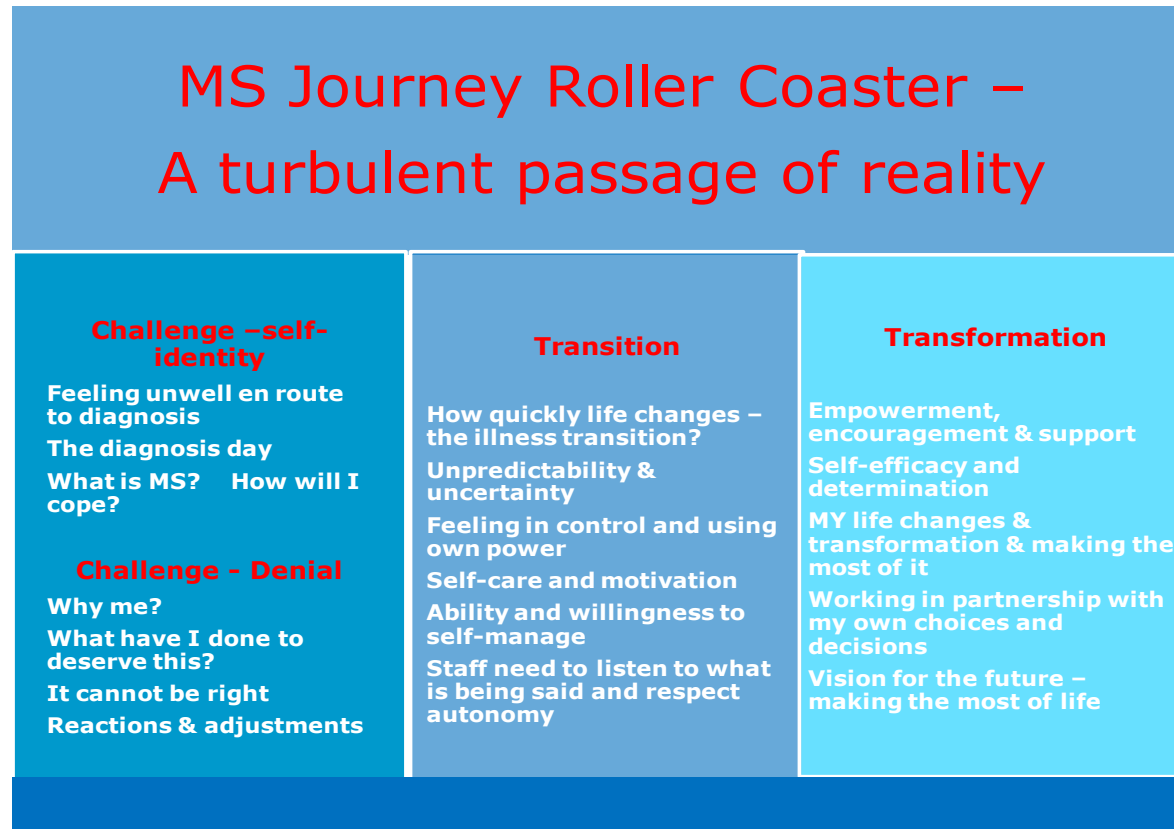
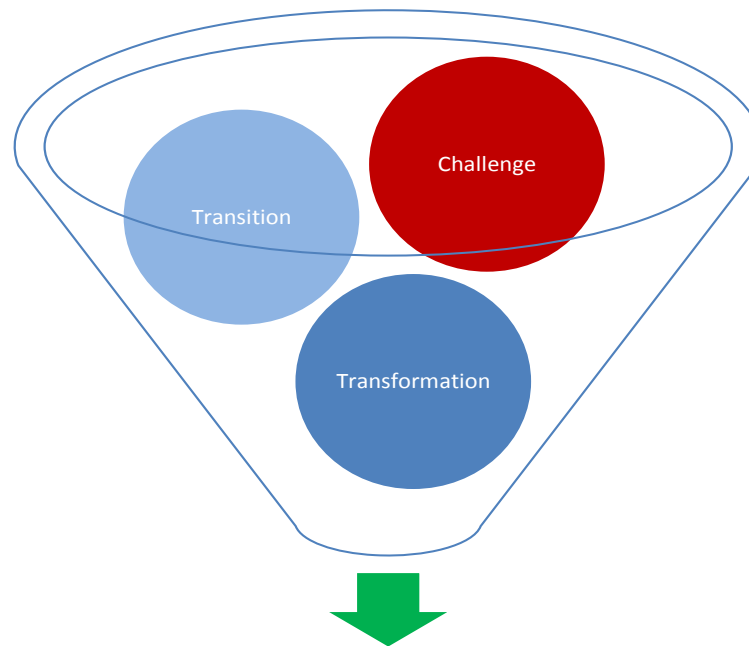


Figure 5.3: Research Themes Criteria



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Figure 5.4: Outlines the central theme with the three main themes in a bubbling funnel to depict the turbulence and the cyclical process due to the unpredictability and uncertainty of RRMS.



The roller coaster of MS: a turbulent passage in reality

Integration of theory

The other major themes clustered and subsumed within larger categories around phases of Challenge, Transition and Transformation and these were related to the central theme through the MS Journey Map Themes (see Figure 5.2) and the usage of analysis maps where the dimensions and properties were identified. A substantive theory emerges from the conceptual categories but is grounded in the data. Overall, the substantive theory was generated around the impact of people with RRMS going through a process of phases of integration through changing their world with new understandings, beliefs and the importance of engaging with self-management and self-efficacy while endeavouring to reach outcomes of maintaining independence, self-control, positiveness, mastery and quality of life.

The themes were sent to the people with RRMS (see Figure 5.3) and their partners/carers to agree or disagree if they were representative of their experiences and they were asked to add their own understandings and meanings to these interpretations. A stamped addressed envelope was included for them to return their comments to the researcher. One telephone and four written responses were received with comments; each was positive and supportive of the themes.

Figure 5.1 depicts life's uncertainties and the unpredictability of living with RRMS which can be likened to a roller coaster. People with RRMS being unsure how things are going to be from one day to the next and having to take each day as it comes and see what they are able to do. At times of relapses or deterioration this can be a very turbulent passage through their RRMS trajectory, other times it can be exciting because they can do more but they are all slightly cautious about overdoing things. It is a common belief among the participants with RRMS that if you bite MS it bites you back and it has sharper teeth than you do. If you do overdo things or try to beat RRMS too much you will pay for it the next few days with tiredness and an increase in symptoms.

Joint Interview 8 with Amy, MS 1 and her Partner

Carer: "You had the lumbar puncture, MRI and the diagnosis and you managed to live with everything that was thrown at you with the diagnosis, you were up and down in your reactions and you adjusted to whatever came to you regardless. You were unpredictable and had lots of uncertainty with the symptoms and recognising when you were unwell. The health and social care professionals were not there or available to you at the early points when you really needed them and you just had to struggle on with things and you kept yourself busy. They should have been there for you to help

you to cope with that part but they were nowhere to be seen. You were flying off at 30,000 feet and then you were digging yourself into 10,000 foot undergrowth”.

MS 1. “Yes that is what it was like with all the ups and downs; it was like a roller coaster it was so uncertain and unpredictable from day to day”.

Carer: “That is my perception of your journey and what this has actually been to me living with you through this traumatic time”.

Partner Sarah, Interview 1

“Oh yes, it went on for over three years because they did not properly diagnose until 3 years ago, so it was really up and down it was a roller coaster but I always think if you are going to stick with something it is worth sticking with. We did not sit down and talk about it because he would not talk about it ever, he never ever spoke about it, you know. He was just going through complete denial, head in the sand he just did not want to know about it or accept it”.

Figure 5.2 is the MS Journey Map exploring the routes which was discussed in Chapter four as a tool which was developed by the researcher following the literature review. It depicts a possible route to self-management and self-efficacy but it is not a smooth journey as people with RRMS go back and forth continuously through the various steps and stages of their personal RRMS trajectory (see Figure 4.2). In this diagram the central category/theme has been applied with the major themes around the steps/stages and the solid red two-way arrows showing the turbulence of revisiting the challenge, transition and transformation. Life with RRMS is very individual and the times of going through the smooth journey vary in length, but there are times of turbulence for many people who can move back and forward. Figure 5.4 outlines the central theme with the three major themes in a bubbling funnel to depict the turbulence and the cyclical process due to the unpredictability and uncertainty of RRMS. This emphasises the importance in stressing these are not completely separate as the trajectory moves backwards and forwards on the roller coaster but often returns to the early stages of the symptoms and disavowal of RRMS.

Computer assisted data analysis

The data analysis was undertaken in several stages using computer assisted concept and content analysis processes. The focus groups and individual interviews with professionals and through longitudinal studies were transcribed and entered into the NVivo 7 CDQMP. Data was grouped according to each research participant and the focus group and then sorted into core categories and outcomes. Memo-writing was done to take stock and analyse ideas about the

codes and emerging categories, to elaborate the categories, specify their properties, define the relationships between the categories, compare data and identify gaps for further data collection. Linkages between the categories were tried and tested until a number of common themes were developed. Memo-writing and diagrams helped with the analysis and reflection of thinking and striking ideas which can help to develop theoretical codes. Aggregation of the data, themes and generation of substantive theory from the research findings were discussed with the supervision team.

The questionnaire was qualitatively analysed for each person with RRMS to see the differences at each of our meetings over the eight month period. The questions were based around self-efficacy and were used qualitatively to see how the responses linked to how the person perceived that they felt during the interview discussions. The key comments that they expressed at each meeting were captured in a tabular format (see Appendix V) to see if they related to their self-efficacy responses. The people with RRMS were asked to respond to each question based on how they were feeling on the days that they completed the scale. It was interesting to see how some of the fluctuations seemed to match how they were feeling or things that had happened to them which they perceived changed their confidence, positiveness, cognition and levels of control. The links and integration of these comments to the quotes used in the findings should be seen in the context across the MS Journey.

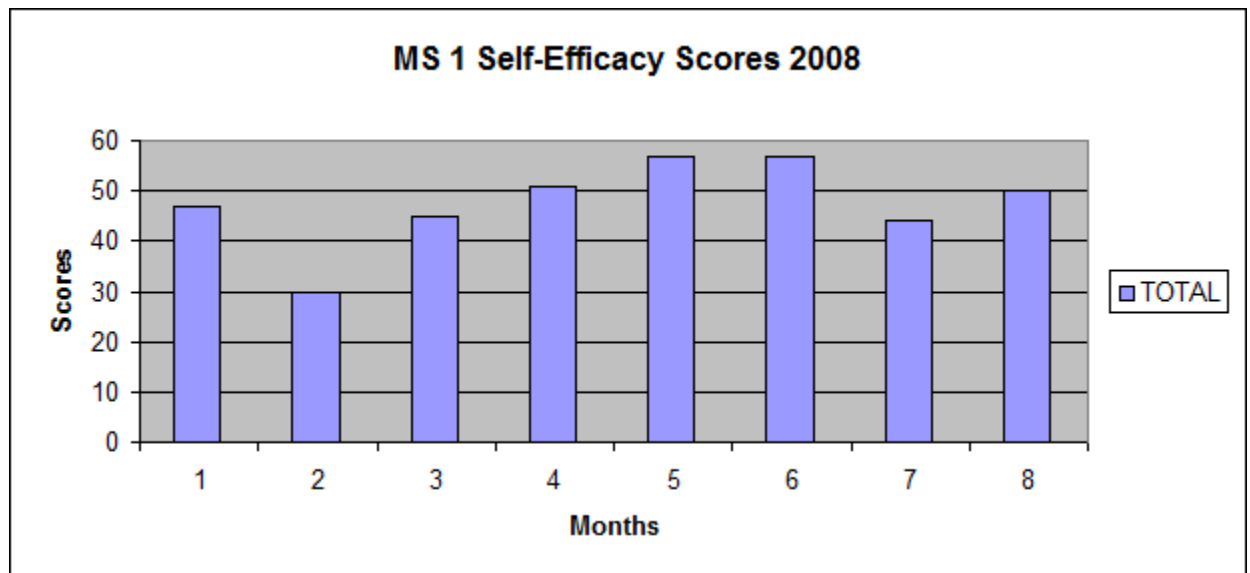
The usage of the longitudinal study which allowed the self-efficacy changes to be captured month by month over the eight visits strengthened this research. Also using the return visits as part of the research theoretical sampling process allowed the demonstrations of the fluctuations over time. A summary of the findings is provided within this chapter to demonstrate the changes over the monthly visits. A copy of the questionnaire used (Rigby et al. 2003) and the full analysis of the individual questionnaires and the tables of findings are available in Appendix V. The questionnaire was a powerful tool which is easy to use in that it could be used at each visit with professionals. It highlights feelings of independence, concern, control and confidence which are useful in assessing the levels of engagement and how the person is feeling during that visit. The people with RRMS could complete the questionnaire while waiting to be seen and it could be discussed as

part of the consultation. The way people with RRMS present at the consultation and how they feel about their current levels of psychosocial functioning could impact on their levels of engaging and being part of professional-patient discussions, choice and decision making. Further exploration of the questionnaire is required, but it could be a useful tool for clinical and research assessments of psychosocial adjustments in people with RRMS.

Summary of the analysis of self-efficacy scores.

The scoring of the questionnaire by the people with RRMS was undertaken at the start of each of the eight monthly sessions based on how the person was feeling on that particular day. Four of them completed it themselves and for the remaining two I read the questions and they chose the options which I then circled for them. There was no discussion around the question areas or the choices they made, prior to moving on to the interviews. The partners /carers were not present when the questionnaires were completed and they were not discussed with them during their interviews. The analysis therefore only includes the discussions with the people with RRMS and what they shared with the researcher during the interview. This reflected back to the last time we met and the issues/perspectives that were shared during the visit in which they completed the actual questionnaire.

The responses were used qualitatively and were compared to the discussions and the issues they raised during the interviews that followed. The next section will go through each of the RRMS Research Participants in turn, from MS 1 to MS 6, with the graph of their monthly scores followed by a brief summary which will be provided to explain possible reasons for the changes in the scores. (Further analysis is presented in Appendix V). It is important that these isolated issues are seen in context as being integrated with the other data sources co-constructed within this thesis. The scores cannot be compared across the people with MS and are only relevant to each individual.



MS 1 Meeting 1 (Score 47)

During the first interview MS 1 came across as a happy and confident person who felt very much in control. She was positive and proud that she had managed to continue to work for 14 years but had recently taken voluntary redundancy as she felt her condition was beginning to deteriorate. She demonstrated self-determination in looking after herself, husband, dog and home; was able to drive and get out and about and stressed the importance of self-management.

MS 1 Meeting 2 (Score 30)

Presented a different person who stated she still felt confident but her persona had changed, the sparkle had gone and she was tearful. She felt her independence was being taken away from her and she was feeling really inadequate as a person because her DMTs were not working and her body was rejecting them. She felt her life was totally in the Consultant Neurologist's hands and it was going to take at least 6 weeks to get the results of her blood sample to confirm the antibodies to the DMTs. She stated she felt like a caged animal as she was now not feeling safe enough to drive and could not visit her mother or her friends.

MS 1 Meeting 3 (Score 45)

MS 1 had been seen by the Consultant and there was marked deterioration in her MRI scan and she was given the prospect of different treatment once the antibodies had gone. She was a different person she looked much better, was hopeful for increased mobility including driving and felt she was on the upward incline. New treatment had been proposed, following six months with no treatment at all, and this had brought relief to her as she felt that something was going to

happen. This was making her feel things were back on the way up and her MS was going to improve.

MS 1 Meeting 4 (Score 51)

MS 1 was much more confident she now had two treatments with the new drug making her feel in control, happy and satisfied and able to drive her car. She still had some worries and concerns in case the treatment did not work and she wanted more than anything else to improve her physical limitations. Treatment dates up to 2014 had been given to her for her monthly infusions and she felt in control of her life again and was hopeful for the future.

MS 1 Meeting 5 (Score 57)

MS 1 had three treatments and although she felt there were no improvements yet, she did not feel any worse than she did. Her walking was very unsteady and she was shaking but blamed it on drinking and cigarettes over the weekend as she had been upset. She was tearful and upset because her dog had to be put to sleep and her husband had returned to work after his surgery. She was planning for the future with her goals and targets including planning a holiday.

MS 1 Meeting 6 (Score 57)

MS 1 was feeling much more confident and was driving her car regularly again seeing her mother and friends. The Consultant had observed her tremors and stated he would give her drugs to sort them out at her next outpatient appointment. She was still having concerns about her condition getting worse but had been informed that the new drug can take at least six months to work. MS 1 stated she felt positive and in control and able to maintain her independence.

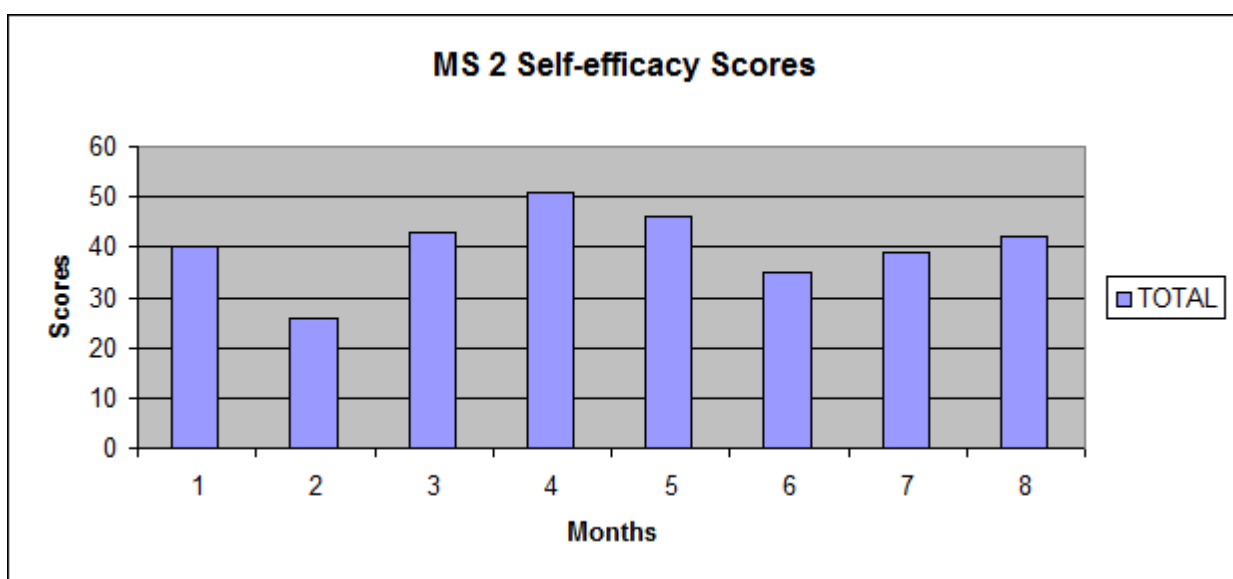
MS 1 Meeting 7 (Score 44)

MS 1 was not so positive today, as she now had 5 infusions of the new drug and had not noticed any changes. Her physical restrictions were making her feel less happy and satisfied but her drive and determination remained. She was worried about her MS and was trying to blank the changes out with disavowal. However she stated that she still felt empowered enough to stop MS from taking over her life. She was looking forward to their holiday and spending time with her husband.

MS 1 Meeting 8 (Score 50)

This meeting was initially cancelled at the last minute as her mother had a bad fall and was admitted to hospital. It was rearranged by her and her husband as they wanted to meet up and share their experiences. MS 1 described her life as a roller coaster, as her confidence and control were fluctuating up and down, and she was

upset again but this time being because of her mother. Her independence had been knocked again, there were no improvements after the sixth treatment and she felt on the top of the ski slope and rapidly going downhill. She was craving more independence but feeling a failure as she was limited in what she could do for her mother. She was trying to integrate the changes into her life to move forward through embracing her MS and not letting it take her over. She felt hopeful and visualised her future and the ongoing support/appreciation of her husband.



MS 2 Meeting 1 (Score 40)

MS 2 stated she was confident, feeling in control and making the most of her life. She did have concerns about her MS getting worse and the kind of impact it would have on her family. The uncertainty and unpredictability of her MS was difficult to cope with but she felt that she manages this by listening to her body and getting through as she does not want to give up. Through being positive, planning for the future and self-managing she felt she could do what she wants when she wants as long as she paces herself.

MS 2 Meeting 2 (Score 26)

This meeting was initially cancelled due to MS 2 not being well. It was rearranged when she felt ready for the meeting but she was still not feeling too good but wanted to go ahead. She had problems with dizziness and walking and also dental problems and have to have wisdom teeth extractions at the dental hospital. She was feeling really frustrated as it was holding her back by limiting what she

could do and making her feel more dependent on her husband and daughter. She was feeling frustrated.

MS 2 Meeting 3 (Score 43)

MS 2 stated that she felt the roller coaster was on the rise with strong confidence and feeling happy and satisfied. She had visited the Consultant at the hospital and both her eyes are damaged through optic neuritis but her sight is okay most of the time. She stated she was fed up with the professional input to her care which was making her more determined to self-manage to cope alone with the help of her family and friends. The fears of her MS getting worse are worrying her but she is determined not to let it interfere with her family life.

MS 2 Meeting 4 (Score 51)

MS 2 was having a good spell and was pleased that her husband has an interview for a job, although she is concerned how she will manage without him, but knows they need the money. She was feeling really confident and happy with what she was able to do. She stated she felt adequate as a person, was back in control of her life including her MS and able to totally self-manage.

MS 2 Meeting 5 (Score 46)

MS 2 was trying hard to keep on top of things and was pleased with herself as due to her exercises and diet she had lost 16 pounds. She was coping with her husband at work and was pacing herself and doing what she could. The planning for her summer holiday and going away was helping with the coping and self-control. There were concerns regarding her cognitive and visual problems and the effects of her MS on her family.

MS 2 Meeting 6 (Score 35)

After a good holiday with rest and relaxation with the family MS 2 was in good form feeling confident, happy and satisfied. She stated she was coping with her self-management, housework and caring for her family. MS 2 felt in control, more positive and coping with her fatigue. She was feeling down because her father had an accident in their motorability car with her daughter in the car, thankfully they were both alright, but the car was a right off. This was making her feel less independent and wishing she could drive to take the burden from her father now that her husband was working.

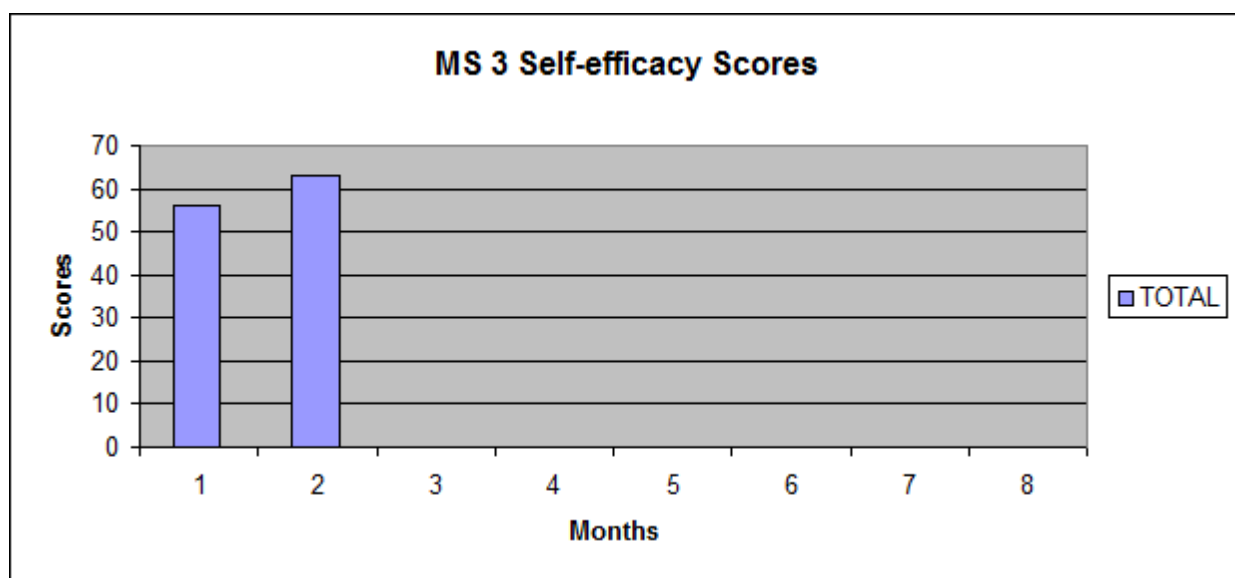
MS 2 Meeting 7 (Score 39)

MS 2 had a birthday and had been out with her MS friends making her feel happy and confident. She was feeling independent as she was coping on her own but

she still felt she needed more independence. Her walking had not been too good and she was using two sticks but doing everything to avoid the dreaded wheelchair. She stated that it is her body and she is in control and is an expert in her MS.

MS 2 Meeting 8 (Score 42)

MS 2 had been unwell and thought she was having a relapse but the MS specialist thought it was deterioration rather than a relapse. She had a bumpy time with walking, dizziness, spasms and pains in her eyes which had all slowed her down and made her more dependent. Her worries were high and she felt she was getting worse, feeling inadequate and in less control. MS 2 was praising herself on her self-management and doing everything herself through sheer self-determination and avoiding a wheelchair at all costs.



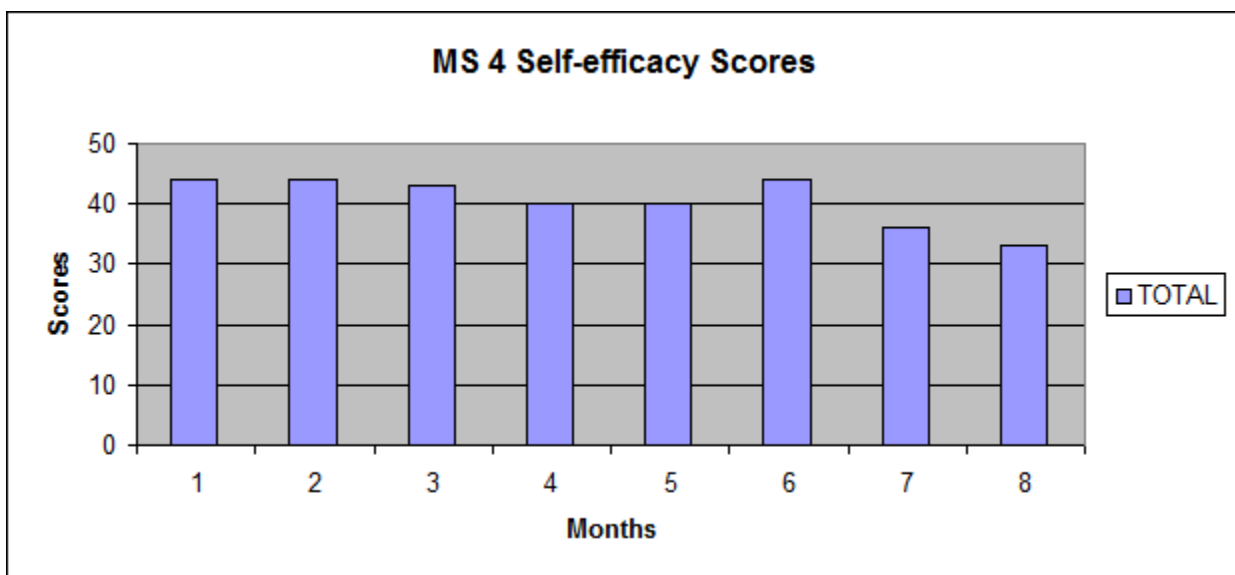
MS 3 Meeting 1 (Score 56)

MS 3 was a positive man who felt very much in control, confident and adjusting well to his changes in lifestyle. He is a very articulate person who feels he can ring the professionals at any time for advice and support. His workplace management have been very supportive of his MS and have adjusted his role and working hours based on what he is able to do. He is very independent and able to get through the system to make sure he gets what he wants when he needs it. He has a history of bad relapses over Bank Holidays and copes accordingly.

MS 3 Meeting 2 (Score 63)

MS 3 had a bad relapse, the worse ever, over the Easter Holidays. He could not drive due to bad optic neuritis and this did knock his confidence accordingly. MS 3

had support from the professionals and cut through the system to get early responses. He had a frustrating time and took a long time to recover and for his mobility and driving to return. He was now feeling much better, was back to work and felt more determined to be more in control of his MS. A further relapse meant he felt unable to continue beyond these two meetings.



MS 4 Meeting 1 (Score 44)

MS 4 came across as a determined, confident and positive person who stated she controlled her MS and did not let it take control over the 20 years since her diagnosis. She felt she had as much independence as she needed, was mobile and could drive, but she did feel a failure at times. She stated that she had a very close family and a good partnership with her husband this kept her in control and able to maintain her activities.

MS 4 Meeting 2 (Score 44)

MS 4 social confidence was not as strong today as she had a fall when she was out shopping and had felt really embarrassed. When I called to check I could visit her, she talked for over an hour about her embarrassing fall, but insisted on the meeting going ahead. She was shaken by it and had hurt her arm and felt the fall was due to her big toe which was really painful and she could only wear sandals despite the wet weather. She did have concerns that her MS might be getting worse and she had not had a relapse for a long time, but this could be the start of the decline.

MS 4 Meeting 3 (Score 43)

The confidence remained high but her toe was affecting her mobility and the restrictions were making her feel inadequate. MS 4 was having difficulty getting an appointment with her GP and feared the receptionist who did not see her as a priority. She stated she felt in control and was able to keep MS from interfering with her family life.

MS 4 Meeting 4 (Score 40)

She stated she was feeling more confident and happier with her MS, but that her toe was causing problems with her walking and balance. MS 4 expressed fears that her MS would get worse and discussed her past peer exercise group and how much worse they all were compared to her. She felt she could still self-manage but wished she could get her toe sorted.

MS 4 Meeting 5 (Score 40)

She was much more positive today following an appointment with the chiropodist and knowing that her toe was going to be sorted out in two weeks time. She was still in much pain and her walking was restricted. MS 4 reinforced her feelings of independence and self-control now that things were happening at last. Her roller coaster of emotions was expressed as ups and downs today as she was positive about her MS but had other concerns which were getting her down. She felt she was self-managing and doing more cooking and housework.

MS 4 Meeting 6 (Score 44)

There had been a break of two months due to severe pain with her toe following the nail removal and MS 4 feeling generally unwell. She was starting to feel better and was self-managing her toe dressings, but was unhappy that she would not be able to go swimming on holiday and was unable to drive. She felt her fatigue was under control but was having increasing symptoms with pins and needles, restricted mobility and feared a relapse of her MS. She stated repeatedly that her self-determination made her positive, independent and in control. She was determined that once her toe was back to normal there would be no stopping her and the holiday was what they both needed to enjoy the sunshine and relax together.

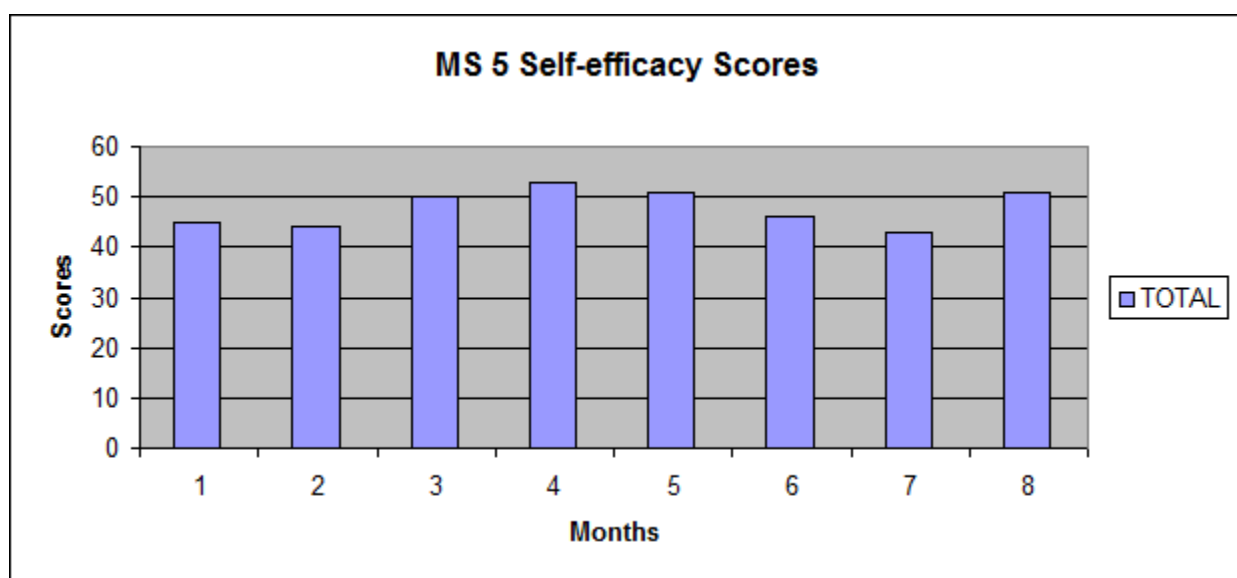
MS 4 Meeting 7 (Score 36)

MS 4 was feeling independent and positive again as she was driving and feeling more mobile. She was active and busy in the home with all her activities but was feeling resentful about the things she could not do. Her urinary problems had

been worse and she was feeling unhappy that her professionals would not allow her to test her own urine, and was worried that her previous kidney problems which resulted in her being in ICU would recur, due to lack of prompt action. She stated she was fully self-managing, more independent, getting out and about, and much more positive.

MS 4 Meeting 8 (Score 33)

MS 4 was not feeling too good today and felt she was getting advanced warning that her MS was getting worse as she had to rest more. She had a bad fall in her bedroom and still had ongoing urinary problems. She was not in good form and was tearful at times. She was fearful of a bad relapse and concerned because with her DMTs she had not had a relapse for a long time and this could be the beginning of a downward slope. She felt these problems needed to be sorted to help her planning for her future and to stop her MS from interfering with her life. She stated she still felt in control and able to make the most of things and this was just a blip she would get over.



MS 5 Meeting 1 (Score 45)

MS 5 is a confident person who enjoys meeting people and has a good social network. His biggest concern is trying to find employment as lack of money is limiting his activities. He is physically active and totally independent. Sometimes he staggers when walking and is embarrassed about this in public places as people think he may be drunk. He stated he does think and worry about the future and his condition getting worse. He sets goals and targets by planning for the future which helps him cope and feel in control.

MS 5 Meeting 2 (Score 44)

MS 5 had a relapse on the day of our last meeting which had affected him for a few days resulting in loss of confidence and abilities. He felt these had returned but was being more cautious not to overdo things which he found frustrating. He had overdone things on a weekend away which resulted in MS biting him back and his slower than planned recovery. He is now back to the gym and doing his Pilates to improve his coordination and balance. He was still doing most things himself but had a few days of optic neuritis when he could not drive and had to rely on his parents for transport.

MS 5 Meeting 3 (Score 50)

He had a confidence boost in meeting other people with MS and their partners/carers at the MS Life Conference. This had made him feel good as he does not need mobility aids as yet but it opened his eyes to the future making him more determined to maintain his mobility as long as possible. He has been having cognitive problems so had been doing memory tests and playing computer games to improve his alertness. MS 5 feels back on target with his goals and control and is pacing himself not to overdo things.

MS 5 Meeting 4 (Score 53)

MS 5 was feeling depressed through reflecting back on his life and feeling he has had no luck for two years which he felt was predominately due to his MS. He stated he is 30 and really wants to work but is having no luck and felt it might be because he honestly declared his MS. He feels he is still confident but dissatisfied with his daily routine and not feeling a useful member of society. He wants to work to maintain his independence and social networking and lack of this is making him feel inadequate. He has not been spending as much time with his friends as he has been travelling to see his girlfriend. He is planning for his future and feels he is doing all he can through remaining positive and managing himself well.

MS 5 Meeting 5 (Score 51)

Today the happiness, confidence and satisfaction had returned and he was feeling more positive. The family had planned a surprise birthday present for his father with a trip to Arizona and MS 5 and his sister had surprised the parents by turning up in Arizona for the weekend. He was feeling good about himself and had potential job prospects. His strategy was to remain personally in control through making the best out of life, but a job would make him feel valued, help his finances and enable meeting more people on a daily basis.

MS 5 Meeting 6 (Score 46)

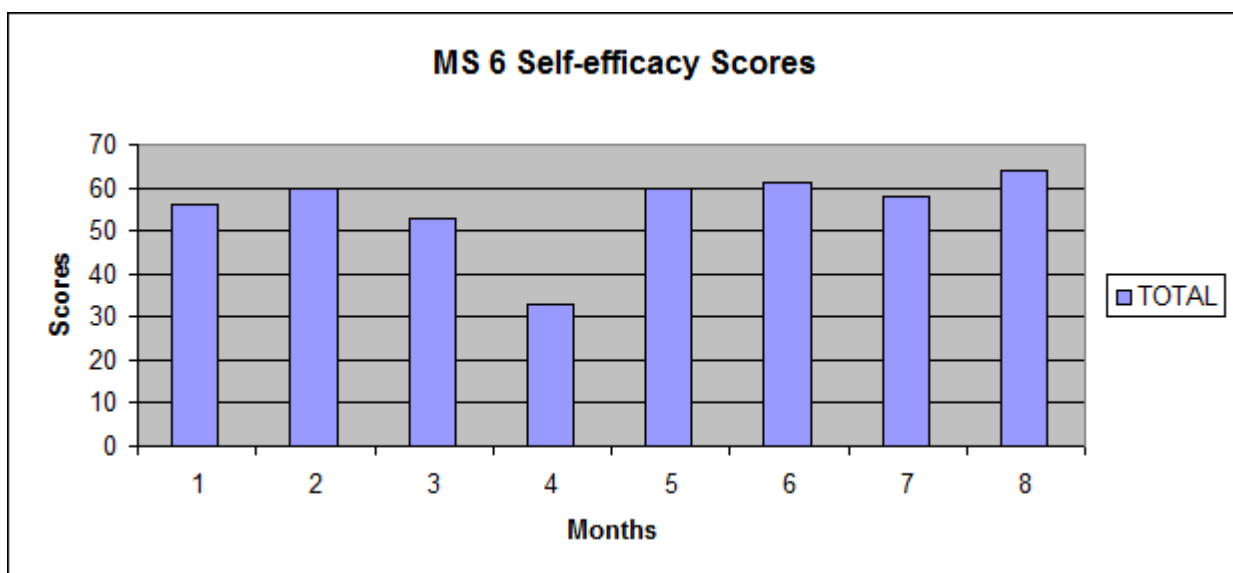
MS 5 was feeling positive and confident, although he had another knock back on a job for which he was interviewed. He was frustrated with what he was doing through the day which was mainly looking for and applying for jobs. He was coping through self-control, doing things in moderation with his self-determination seeing him through. MS 5 is enjoying the gym and keeping in shape and looking after his health and wellbeing. He desperately wants to work and feels he needs to socialise with more people.

MS 5 Meeting 7 (Score 43)

MS 5 was bored and annoyed about the lack of employment which is making him feel dissatisfied and unhappy with his days which are spent with unsuccessful job seeking. His independence is still present and he is pacing himself in terms of his activities and maintaining control of his MS. He is looking after his flat and feels he is totally self-managing. He is still managing his cognitive problems but feels frustrated that his memory lets him down at times.

MS 5 Meeting 8 (Score 51)

Today brought high levels of confidence, independence and satisfaction. He was meeting people through attending the Employment Opportunities Course and doing ECDL training. MS 5 was trying to improve his social life and looking after his health and wellbeing. He was concerned about the future and what would happen next if he again reaches the tolerance level of his drugs. He stated that MS was a big part of his world but it was not his world as there are lots of things he needed to do to balance his life, even if it meant taking calculated risks to allay his worries and anxieties. He stated he will remain in control and he knows what is best for him through remaining positive.



MS 6 Meeting 1 (Score 56)

MS 6 came across as a very confident man who was outgoing, enjoyed company and stated he was making the most of his life and not dwelling on MS. Despite limited walking he remains mobile mainly through use of his scooter, a wheelchair and walking with crutches. He goes to the job centre every week looking for suitable employment. He stated that he has never felt like a failure as he does everything that he can himself, he controls his fatigue, remains positive, determined and empowered.

MS 6 Meeting 2 (Score 60)

MS 6 tends to have annual relapses in March each year so in order to prevent this, his GP persuaded him to try prospective steroids as prevention. Each time he has steroids he has bad reactions to them and this time was no exception. He felt totally fatigued, lacking in coordination and movement and this went on for over a week. He still maintained strong feeling of independence, coping mechanisms and positiveness in coping with his MS. He feels he makes the most of his life and is happy with it.

MS 6 Meeting 3 (Score 53)

MS 6's confidence was not so strong today due to the ongoing effects of the steroids but he felt there were slow improvements with his physical condition. His mobility was not as good and he was not able to walk at all and has not been out on his scooter so was feeling caged in. He stated he was making the most of his time in the house reading and playing chess on the computer. He did not feel he could plan ahead but was taking each day at a time until things were back to normal.

MS 6 Meeting 4 (Score 33)

This was not a good day and MS 6 thought he had a relapse as he was feeling stiffness and lethargy. For the first time he admitted that he strongly felt he did not have enough independence. He stated he could self-manage his personal hygiene and toilet needs but not much more. He had also had a fall and felt that MS was in control for the first time but that it was only temporary.

MS 6 Meeting 5 (Score 60)

MS 6 was feeling stronger and more confident today apart from feeling stiff and a bit weak. He said that he felt much better and that these effects were due to a bug and not his MS. He felt his independence was back and that he is back in control of his life and activities. He was still concerned about his future and that it is

nearly a year since the started planning for a downstairs bedroom and wet room but still without the go ahead of the council and PCT. He feels there are physical barriers but that nothing is an obstacle when there are ways around it which he plans and orchestrates.

MS 6 Meeting 6 (Score 61)

MS 6 felt he was still weak and fatigued but that he was on the way out of it now, but that it was not the MS that had been causing it. He felt he needed to push himself more and that is was mind over matter but his strong mind means he is in control. He stated his independence is strong, he is in control and his self-determination will see him through this.

MS 6 Meeting 7 (Score 58)

MS 6 had a bad fall this morning but insisted that the interview went ahead although he had banged his head but stated he had not hurt himself. He stressed he was confident and in control having the level of independence that he needs. His activities are increasing and he is doing more self-management and requests support when he needs it. He stated he has accepted MS as part of his life but he is in control and it will not overtake his life. His lifestyle had changed and he was more sedate, but he stated he is personally very much in control.

MS 6 Meeting 8 (Score 64)

He stated his confidence had returned but admitted the last relapse has left damage with numbness and deterioration. He felt he was winning as he managed to walk a few steps with his crutches. He is back out on his scooter and strongly feels he is again more independent and back in full control. Planning for the future was helping him cope with his MS and he is working with his family to make it happen. The extension had been given the green light at last and is planned to start in 2 weeks time. He stated that his goals continue with self-management, keeping his mental strength over his physical abilities and being positive. He stated that MS can try and restrict his freedom but he will always find a way around it.

(Further details of the full analysis are available in Appendix V and should not be viewed in isolation but in the context and with full integration of all the research findings).

Theoretical saturation

Grounded theory has a built-in mandate to strive towards verification through the process of category “saturation” which is achieved by staying in the field until no further evidence emerges. Verification is done throughout the course of the research study, rather than assuming that this is only possible through follow-up quantitative data. The developed theory should also be true to the data, it should be parsimonious (Strauss & Corbin 1998). Theories develop using the grounded theory methods as interpretations which are made from the given perspectives as adopted by the researcher who needs to remain open to the essential provisional character of every theory. A theory provides the best comprehensive coherent and simplest model for linking diverse and unrelated facts in a useful and pragmatic way. It is a way of revealing the obvious, the implicit, the unrecognised and the unknown.

Theorising is the process of constructing alternative explanations until a “best fit” that explains the data most simply is obtained. This involves asking questions of the data that will create links to established theory (Morse 1994). Theory is a set of relationships that offer a plausible explanation of the phenomenon under study (Strauss and Corbin 1994). One of the key aspects of grounded theory is the generation of good ideas through the theory testing and application.

The developed concepts will be explained theoretically and applied to the findings in order to give meanings to description of the behaviours in Chapters six to eight. I was striving to provide current interpretations of the data as an honest representation of the participants involved in the research study. This was undertaken by thinking abstractly and theoretically rather than descriptively when dealing with the data and therefore took time to ensure completeness. The labelling of the categories was from the theoretical explanations of behaviours within the recognition of context and change. I tried to be creative in providing my own names for what was going on and used some *in-vivo* codes. Then I described the conceptualisations of the categories in terms of the particular properties and dimensions that were evident in the data. Later, in writing up my findings, I made comparisons describing how my conceptualisations of data extended or fitted within the existing literature. Once I was engaged in the process, rigour and credibility stemmed from the full and reflexive interrogation of the data in order to

allow the theory to emerge. Rigour in this process is reflexivity grounded in actual experiences of the research participants.

In line with the interpretivist philosophy, it was important to recognise that enquiry is always context bound and facts were viewed as both theory laden and value laden. The idea that findings are theory laden rests on the basic proposition that I approached the research situation with a theoretical perspective developed from my academic background and personal interests. Most researchers will also have their own personal paradigm or basic belief system, their values, which will largely dictate ontological and epistemological underpinnings (Strauss & Corbin 1998). According to the grounded theory philosophy knowledge is seen as actively and socially constructed with meaning of existences only relevant to an experiential world. Therefore the focus was very much based on one of how people behave within an individual and social context.

Co-construction of meaning in qualitative research

In considering rigour in grounded theory it is important to pay attention to the social construction of knowledge and the research relationship which are important in data collection and analysis and the development of the emergent theory. It is important to include reflexivity and relationality in the grounded theory design in order to attend to the effects of research-participant interactions on the social construction of data and of trust and power relationships. Reflexivity addresses these issues and provides a self-critical awareness of the ways in which the researcher as an individual with a particular social identity, political awareness and professional background has an impact on the research process. The issue of rigour in grounded theory studies must pay attention to the social construction of knowledge and research relationships to ensure the data collection and analysis informs the emergent theory of the project. This is grounded in the ability of the researcher to put aside personal feelings and preconceptions, it is more a function of how reflexive one is rather than how objective one is, because it is not possible for researchers to set aside things about which they are not aware (Ahern, 1999). Strategies for dealing with threats of researcher bias included the researcher spending a substantial length of time in the field, the triangulation of multiple data sources including recording observations, and care with respect to the researcher's social behaviour in the field.

However Johnson & Duberley (2000) argue that any theory of knowledge presupposes knowledge of conditions in which knowledge takes place. This suggests that the research participants and the social context in which the research takes place should also be considered when planning the research design through the data collection, data analysis and report writing. Researchers have to apply reflexivity to the process of doing research, their relationship within the research context, the research participants, the resulting data, the writing up and the presentation of the research. They have to critically examine, explain and re-examine all that they do as a researcher. They can also engage the research participants by inviting them to be reflexive about their role and in the researcher's presentation in the research results. They can also engage their supervisors and critical colleagues in reflexivity when the researcher discusses and presents their research. In contrast, Pels (2000) states that reflexivity often parades in a show of confessional virtues (for the researcher but sometimes for the researched too) such as the courage of 'opening up' the candour of 'telling where you come from' 'the correctness of taking responsibility of your roots' and the consistency of 'not making an exception out of yourself.' It is therefore important to be aware of the effects of researcher-participant interactions on the social construction of data and of power and trust relationships. In this research an equal relationship of trust and power was quickly built up and the research participants were very keen to be involved, looked forward to the discussions and welcomed the researcher into their homes in sharing the MS trajectory.

All researchers have preconceptions whether they come from previous experiences or pre-existing theory and it is important for them to actively work to prevent these from narrowing what is observed and theorised and how this is interpreted. It is argued that each methodology suggests that awareness of the tension between distancing and immersion is necessary in order to establish rigour and trustworthiness (Koch, 1995). The researcher's own experience will inevitably have effect? In terms of historical, cultural, personal and professional background (Gadamer 1976). The researcher of this project, as a senior nurse manager and healthcare director may bring pre-understandings and prejudices to this research study and no attempt can be made to disguise these, so it was important for me to make my concerns and position clear. The research participants have been made aware of my background but have been clearly informed repeatedly that my role in

undertaking the project was to learn from them all about RRMS, and that I would not be participating in their care. Cross data analysis was undertaken at the start of each interview session by checking the research participants' agreement with the summary of the previous discussions within the last interview and allowing them to expand further on any of these areas. The need to demonstrate integrity and rigour of the research was the key endeavour. Throughout the discussion, consideration has been given to the various steps taken to ensure, as far as possible, that the study was rigorous in conduct through the systematic and transparent data collection, analysis and interpretation of the data.

Conclusions

Data generation and analysis occurred concurrently, which enabled the identification of emerging themes and issues from early data to guide future meetings and topic areas to guide the discussions. The main issues from the previous interviews were presented and confirmed with the research participants at the beginning of the next meeting session and the themes were agreed with them after the data analysis. The decision trail and the aim of writing through the research journey allow you to follow the way in which the research has been undertaken. During interview eight the people with RRMS set out their own personal journey maps which are available in Appendix VI. Seeking understanding is the aim of qualitative research and interpretation is about making sense of what have been learned through the research process.

The aims of the study were to develop an understanding of the engagement process and the different levels of involvement in self-management and self-efficacy undertaken by people with RRMS from their perspective. The views and levels of support from the professional and partners/carers were also important in understanding the engagement process across the RRMS trajectory. The journey has involved six people with RRMS and their partners/carers over an eight month period where information rich discussions have explored the RRMS trajectory. There were also discussions with sixteen professional carers who provide ongoing care to people with RRMS. Through working with these people over fourteen months I was given the opportunity to go through their journeys with them listening to them sharing their experiences, frustrations, emotions and memories of how RRMS has featured in their lives and exploring ways that improvements could be

made for all people with MS. These experiences are shared throughout the next three chapters which will provide the opportunity for the reader to hear what the research participants have to say in their own words as the RRMS journey continues.

Chapter Six: Challenge

RESEARCH FINDINGS

Central Theme – MS Journey Roller Coaster – A turbulent passage of reality
Major Themes – Challenge, Transition and Transformation

SUB THEMES	CHAPTER SIX: MAJOR THEME- CHALLENGE
Losing control of self-identity	<ul style="list-style-type: none"> Feeling unwell en route to diagnosis Reflecting on the diagnosis day What is MS? How will I cope?
Denial or Disavowal of RRMS	<ul style="list-style-type: none"> Why me? What have I done to deserve this? It cannot be right Reactions and readjustments

SUB THEMES	CHAPTER SEVEN: MAJOR THEME – TRANSITION
Engagement in the process through taking more control	<ul style="list-style-type: none"> How quickly life changes – the illness transition? Visible and invisible symptoms Unpredictability & uncertainty Feeling in control and using own power
Ability and willingness to self-manage to accommodate RRMS	<ul style="list-style-type: none"> Learning to live with RRMS Self-care, coping and motivation Ability and willingness to self-manage Staff need to listen to what is being said and respect autonomy

SUB THEMES	CHAPTER EIGHT: MAJOR THEME – TRANSFORMATION
Accepting the intrusion of RRMS and regaining control	<ul style="list-style-type: none"> Empowerment, encouragement & support Self-efficacy and determination MY life changes & transformation & making the most of it
Embracing RRMS and moving on and making the most of life	<ul style="list-style-type: none"> Reclaiming life 'I have MS but it does not have me' Working in partnership with my own choices and decisions Vision for the future – making the most of life

Introduction

The first chapter of the research findings describes the early phases of the RRMS trajectory through the roller coaster ride of the turbulent passage of reality. It has described the first major theme of Challenge in terms of the constructs self-identity and disavowal/denial. The main themes follow the tool of the journey map (Figure 5.2) where they have been applied to the MS trajectory route. In order to illuminate the nature of the research participants' experiences their quotations lead the discussions with the theoretical underpinnings appearing after each section and summarised at the end of each chapter. The quotes chosen from across the longitudinal study represent the generated themes from the data analysis.

This chapter begins with the presentation of the RRMS journey through listening to the voices of the people with RRMS, their partners/carers and the professionals. Through learning about the experiences they were prepared to share when engaging with the research approach; about what it was like to receive the

diagnosis and coping with the reactions and adjustments to accommodate RRMS and seeking out reasons and opportunities to move forward. The storyline moved through the two major constructs of the Challenge theme which were identified as Self-Identity and Denial or Disavowal. Under the challenge of self-identity the chapter discussed the journey to the diagnosis; the day of diagnosis; telling people about their diagnosis; and what the diagnosis meant, including how they would be able to cope. The challenge of denial/disavowal discussed the ways the people with RRMS protected themselves against the diagnosis; and the specific reactions and adjustments to knowing that they had RRMS.

The initial challenge for the people with RRMS was trying to understand why they felt unwell and had bizarre symptoms, which seemed to come and go and were attributed to various things such as sleeping positions, stress, ear infections and flu. But when the symptoms continued to return and interfere with their functioning and their lives they felt the need to take action and find out more. The partners/carers were expressing concern at this time and were also baffled by what was happening and trying to explain the symptoms. The engagement process with each other and the healthcare professionals at this time is high in terms of trying to find out what is wrong and to seek meanings and solutions for the disruptions to life.

Challenge – self-identity: Feeling unwell en route to the diagnosis

Self-identity is the way in which individuals see, describe and define themselves through the experiences that they feel, and what they mean to them and how they affect their lives. Self-identity changes over time as people make new allegiance and are subject to pressures, challenges and changes in how individuals' see themselves and their world. In this research the people with RRMS discussed feeling unwell en route to the diagnosis and described how they felt, acknowledged and eventually dealt with the symptoms they were experiencing once the symptoms started to invade on their lives. The experiences and symptoms of each person affected them in different ways. MS is a very individual illness, with an uncertain and unpredictable course from person to person, and even within the same individual over time. The six people with RRMS all began their journeys with bizarre symptoms which were alien to them but often ignored, minimised to make them appear normal or thought to be due to other causes and effects. Such elusive

symptoms are often so nebulous that they are often attributed to stress or perhaps a trapped nerve and people often delayed going to the GP until the symptoms were more troubling. The individual chronology was different with each person and appeared unique to them. They all had high levels of engagement with the healthcare professionals during this time, using the biomedical and psychosocial models, to try and find out what was actually wrong and to have the symptoms validated and a diagnostic 'label'. Some people once they were actually diagnosed could reflect even further back to when they had strange things happen to them but just laughed them off or minimised them. MS 2 described how she felt when she was feeling unwell for a long time prior to getting referred to a Neurologist.

"When I was first poorly I was like starting to shake and I felt really, really dizzy. I was having trouble, falling down the stairs and that, and my fingers felt numb at the bottom, my legs were like sore and tired and heavy. So that was mainly the problems when I was starting to feel bad and that and the dizziness was the worst". **Michelle, MS 2, Interview 1.**

When she reflected back over a number of years to the symptoms that she could clearly remember now, but at the time she had just brushed them off as not being important. Her father's wife had MS which was helpful to her in the lead up to the diagnosis. She stated that she had diagnosed herself following the results of an MRI (magnetic resonance imaging) scan which was undertaken to assist in the potential diagnosis of ear infections related to the constant dizziness she was suffering.

"My legs just kept being sore and my husband and I were always laughing about my gammy leg again because as we were walking along my right leg would just drop and we kept thinking why is it doing that *Laughter* ++++. So I have had MS for at least 10 years but only actually had a proper diagnosis for 3 years". **Michelle, MS 2, Interview 1**

MS 5 was a young man at University when he first started to recognise symptoms, but at the time he did not know what they were, and sought help from a local GP as he was living away from home. He was unsure whether he was being perceived as a malingerer or just trying to get out of his exams at the time.

"I will start with what I now know was an attack when I was not well and went to the GP and she thought that I was trying to get out of doing my exams at University. It was a very stressful time; I had numbness from the waist down and knew something was just not right. I can clearly remember it and I now know that stress can be a factor that can trigger off the MS, and it was indeed very stressful. I was in Scotland and had a GP there but she did not really know what it was and thought I was making it up at that time of my 3rd Year exams and in time the symptoms disappeared. Then when I was in the fourth year and again indeed it was a stressful time with my final exams and I had symptoms but I had felt like this before but I did not know what they were and did not really care at that point. I had a lump in my throat again I asked my GP about it and I was stressed again and the GP said it was okay and that he would keep an eye on it. Again he did not seem to know what it was but at least he said he would

keep an eye on it which was a damn side more than the previous GP had said. So that was okay and that just went away and then I finished my degree. Randomly over this time I was getting my words mixed-up and I was not pronouncing words clearly or getting them out properly due to speech problems". **Ian, MS 5, Interview 1.**

The MS specialist professionals are aware of the early symptoms and the responses that people get from their GPs and other professionals who try to use their knowledge and power to test out their own decisions. This can cause delays in referrals which can be frustrating for people with bizarre symptoms. Since everyone with potential MS symptoms may have different experiences and GPs do not see many people with MS, it is difficult for GPs to build up any sort of expertise in diagnosing the symptoms. MS is an intermittent, fluctuating condition that can take a highly unpredictable and uncertain course of events which can be difficult to recognise and treat. MS complicates the diagnostic process as the symptoms can vary in severity and be transitory in nature.

"Some people have had vague numbness and tingling or blurring visions and go to their GPs and often they might be dismissed. I think when you talk to people with MS although some of the things sound very vague and sounds like things we have all had like numbing patches and my legs felt heavy. You think you are describing something that is very familiar to you, but when you listen to them they knew it was not right or it was different or it was something more than just what a normal person would experience, it was not just having lain on the arm". **Professional 3.**

There has been much raising of awareness by the MSS and the media and now many people have heard about MS or know someone who has MS. This has also helped professionally as referrals with symptoms are being made more quickly and this is probably helped through the promotion of better treatments to help control the relapses.

"A diagnosis of MS is not generally everybody's first thought it is usually when they have had a tingly episode and maybe it is only when a pattern develops of more than one that the penny drops and they get referred to us. A lot of them will present to their GP or other doctors with a very obvious symptom like optic neuritis where they have gone blind in one eye. They will see the eye doctors who as time changes, in the past often they will go away without MS even being mentioned. Now that we are more aware of the early treatment of MS we are seeing more of these people at their very first episode". **Professional 3.**

The Partners/Carers also raised a number of concerns and wanted to find out what was happening and why symptoms were occurring but nothing was initially detected as being abnormal.

"It started really from when a few times his leg would go funny when it would just shake. I did wonder at the time what, and he had gone to the doctors and the doctor said it was nothing, and I was thinking why would your leg shake uncontrollably with absolutely no reasons at all. I kept saying to him you know I would go back to the doctors I am not happy, I am really not happy about it". **Partner, Helen, Interview 2.**

The concerns were raised further when it affected her husband's own safety with risks being taken which were having an impact on his job and potentially the safety of other employees.

"I am a worrier and I know I am and I just started to worry about things and it was not until he started getting the pins and needles and the numbness in his hand that he knew. Then one day he was pushing one of the big trolleys at work with the groceries on and he could not stop it as he could not hold it and he let go of it and it went down".

Partner, Helen, Interview 2.

The early fluctuating symptoms prior to diagnosis can be frightening, challenging and stressful as they are often unnoticeable and invisible to others and may even disappear. At times it can also be difficult to gain support from partners/carers, family members and professionals who may all support the minimisation. It is often not until they are taken seriously by the professionals that people begin to believe they are real and do exist and are validated by investigations being undertaken to try and diagnose the problems. The physiological symptoms and the affects they were having in terms of disrupting their lives and work were getting people to think about their own self-identity in terms of imagining what was going on or possibly being a hypochondriac or malingerer. People's reactions and feelings during the diagnostic period can vary dramatically in terms of how they cope and the worries they have as to what may be causing the symptoms. The time was described as being in limbo because their lives and the lives of the families are seen as being suspended in time as they await news that will confirm what is wrong and how the symptoms might be controlled to allow things to return to normal. During this time people were partially willing the professionals to engage with them and tell that what was wrong and partially wishing it was a bad dream which would just halt. The journey to a diagnosis of MS was described as always seeming to be long, stressful, uncertain, worrying and wondering what on earth was wrong.

"I could not do my job properly so I decided that I would have to go to the doctors to find out what this was, so I made an appointment at the doctors and she said there are many, many people that come in here with pins and needles it's probably nothing. And she said just take a bit of time off, I'll give you a few weeks sick note to last you through just so that you can rest yourself and see if you get any better. I went to the RVI, in a private unit of the RVI, I'd been recommended a consultant I should see and I went to see him. This was a really challenging time for me. Then I went back to see the same consultant he suggested I should go and have a lumbar puncture and MRI. It was all taking ages, and this was private, and I was worried, frustrated and wondering what on earth was wrong with me". **Amy, MS 1, Interview 1.**

The journey pathways of the six RRMS participants had some similarities from the first recognition of actual symptoms to the actual diagnosis, but the time span ranged from four months to six-and-a-half years. They all described difficulties in

coping with the symptoms and feelings of losing control over their bodies or the messages from their brains not getting through to the actions that they wanted their bodies to take which resulted in walking into things and falling over. The symptoms were often unrelated raising anxiety and confusion as they came and went.

“It was like the messages were not getting to him and he was starting to wee himself and the messages were not getting to his brain. He also used to get pins and needles in his hands and I used to massage his hands. It was his balance as well, if we were out he used to go off balance a bit and people used to think that he was actually drunk, it was embarrassing because he used to hold my hand and pull me over as well”. **Sarah, Carer, Interview 2.**

The pre-diagnosis time can be really stressful and does cause uncertainty while the investigations are ongoing. Some people expressed anger and disappointment that this could take such a long time while they suffer symptoms and are very unsure what is wrong with them. Worrying, waiting and wondering formed the journey to diagnosis, with fears such as tumours and cancers along with the inner anxiety, loneliness and silence. There are no answers at this time only more questions with a waiting time which is filled with frustration, prolonging the agony and increased uncertainty within the rocky roller coaster journey. Some people renegotiate their self through accommodation and acceptance by engaging with professionals to share with one another their knowledge and expertise. While to others there is a chronology to the trajectory which they accept and they described as feeling like life is at a standstill waiting for the diagnosis. They also fear that people do not believe them, because the symptoms may be invisible and they may not be taken seriously by family and friends, who may think they are a hypochondriac.

Challenge – self-identity: The day of diagnosis

The diagnosis of MS is based on clinical data and the exclusion of other similar conditions. Due to its complexity and variety of symptoms it is not easy to diagnose MS and there is no single diagnostic test. There are a number of tests and procedures that people have to go through such as neurological examination and history; MRI scan; evoked potentials; lumbar puncture and blood tests. These tests take time so it is not surprising that the pre-diagnostic phase may be prolonged, filled with uncertainty and frustration. The actual causes of MS are unknown, there is currently no cure and there are limited treatment options to control relapses with drugs and therapies to help symptom control. Receiving a diagnosis of MS has many implications for patients' lives both physically (e.g.

physical limitations and fatigue) and psychologically (e.g. cognition and depression) which can impair their quality of life.

Engaging with professionals for a diagnosis

People with RRMS talked about engaging with the professionals in order to try and find out what was actually wrong to try and alleviate their fears and to actively get some form of diagnosis. Three of the six people with RRMS actually went for private healthcare to speed up the diagnostic process to find out what was wrong so they could regain control over their lives.

“I think the best way to describe the day of my diagnosis, and it is going to sound weird, but I actually felt relieved. I knew MS wasn't life threatening, I knew you couldn't die from MS. I knew you could have problems with your balance, you could have problems with your sight, you could have problems with your motivation and your mobility, but I had gone through the usual role of cancers and different things, brain tumours and things and because it was my right side I'd had sort of considered that I may have a brain tumour or cancer somewhere”. **Richard, MS 3, Interview 1.**

“I was really scared as what he was going to say to me because I thought I had a brain tumour or something like that”. **Michelle, MS 2, Interview 2.**

“I was then relieved that the good news was that it is was not a brain tumour or something worse. I was convinced in my own mind that it was MS even without the diagnosis. I was thinking the good news was that I did not have a tumour but I did have MS. This was a real challenge for me and I thought how will I cope with this and my job and my life”. **Professional 2 (who is also a person with MS).**

“Other people's concerns are not so much have I got MS, but are really worried that it might be a brain tumour” **Professional 1.**

The day of diagnosis for the six people with RRMS in this research study took between 4 months and 6.5 years with half of them receiving a diagnosis within 2 years. Travelling the journey is different for each person and some find it lonely, feeling pressures and heightening vulnerability and alienation. Two participants underwent the investigations and a diagnosis of RRMS was recorded in their medical records and, although they suspected the diagnosis, they were not informed until sometime later. One of the participants read it on the computer screen in her GP's surgery and the GP was really surprised that she did not know and Michelle (MS 2) was really annoyed that they did not even tell her that was what they were investigating. The other participant, Ian MS 5, was not informed immediately, it was a few years before his GP actually told him. He described how he went into immediate total denial by keeping his diagnosis a secret and concealing it from others.

“Everything was just kind of kept back too much it was not until I read my doctors notes on the computer when I was in there and I found a diagnosis for MS and she

went did you not know and I went no. So I was in tears because I did not know. And I thought why keep something like that from me why did the consultant not say by the way we are checking you for MS – we are not saying you have got it but we are going to check. They treat you like a 10 year old, but he did not say anything at all and that really upset me. I was sad and upset, mad that it took so long to find out that there was something wrong with me or what was wrong with me because I knew that there was something wrong with me. Just the time thing and it was just, I cannot really put words to it but I think it changed the way I was for a little bit”. **Michelle, MS 2, Interview 3.**

“But I did not find out myself until my GP told me a good few years after that so that was an actual diagnosis but that was when they told me and then the denial began. He did try and explain things he said currently you are okay and it is not going to kill you at this hour. So it was okay for me to continue with myself and going to work before I went down South. Which I did do but at the same time after I was told I did not want to share it – I did not even want to tell my best friend or anybody else. My GP did try and explain things he said currently you are okay and it is not going to kill you at this hour”. **Ian, MS 5, Interview 1.**

In the earlier discussions with the professionals there had been a review of how people reacted to the diagnosis and how the news was given to them.

“Some people talk about things coming their way for a while and I think there is often relief at validating that there is something wrong with them. Other things that could be wrong with them such as cancers or brain tumours as such I am not sure that a lot think that or that it would even cross their minds”. **Professional 3.**

Every one of the people with RRMS has a story to tell of their experiences during their trajectory journey, especially on the day of their diagnosis, and the profound effect it had on their lives. They could clearly remember what was said, where they were and how they were positioned and the after effects of what they did for the rest of that day. “You have MS” they described reactions of numbness, shock, and feeling really stunned when they heard the news and being emotionally wounded and there was a lack of empathy. How would they learn to live with MS when they felt as if they were losing control and wanted to continue with normal life activities as much as possible? They described a dilemma as well as a challenge to receiving the diagnosis as there is no cure for MS and the treatment does not assist the disability just the relapses. There was also the realisation that they may never get off their roller coaster ride if this was their future.

“The Consultant called me back to the private ward and he said right all I can say is you’ve got a problem in your neck and yes I can see you’ve got a problem in your neck. My husband was sitting behind me and I thought whatever he’s going to say to me now I daren’t look at him because I’ll cry. The Consultant said well what I can tell you is, just straight out with it, you’ve got MS and I’m thinking MS what is that? I had no idea what it was, never heard of it at all, so he gave me a phone number to call for the MS Society to get all the information I needed, and he give me some very, very wise advice, from that appointment, I presume, I’ve kept it in my head every since. You know it was if you want to go home and you want to feel sorry for yourself and you don’t want to do your shopping and you don’t want to walk your dog and you don’t want to drive your car I can assure you you’ll be in a wheelchair in three weeks. You remain in that positive mind, you do everything you always did before, drive the car, go to work, do your shopping, walk your dog, you’ll be fine, and I was up until last year

when I finished work. As soon as I was out of his room I broke my heart. I knew it was serious but as I say I didn't know what it was I had no idea". **Amy, MS 1, Interview 2.**

The Consultant Neurologists feel that the awareness of MS is higher than it used to be and that by the time it comes to the actual diagnosis that many people may have worked out for themselves that they actually have MS. There seems to be a process of reality adjustment which is unique to what RRMS might be compared to other LTCs.

"It is a disease that most people I think in their 20s now will vaguely be aware of because of TV shows and publicity campaigns. So that has been good in a way and that you are not going into it completely cold when I say to them "I am sorry it is MS". I do not get the feeling that it is not something that they have never thought of. Often I get the impression now increasingly that it has often been on people's minds. You are then in the situation because of the publicity of MS tends to be morbid of people in wheelchairs then they think they know it is MS and they think they know what MS is then often that is quite a catastrophic thing because they assume you are telling them that they are going to be handicapped and soon". **Professional 3.**

The way they break the news to the patient on the day of diagnosis seems to depend on how much awareness of MS that the person has and whether they feel that the patient has an inclination that they have MS.

"The Consultant was laughing and happy all the time and he says right after about half an hour he says do you want the good news or the bad news and I says well I'd like the bad news first and he was sitting opposite is and just glaring at us and grinning all the time. He says well he says I think you have Multiple Sclerosis and he was just laughing and I just couldn't believe what he'd said and then he said but I think you're lying to me, he said I think you thought of this before and never said, you know he says so you've been keeping this to yourself haven't you? I supposed I had really because I'd read books and all kinds read loads of different things what I could have and when I read about MS I thought well I'm wrong, couldn't have that, that's just stupid and I put that out of me mind, I thought no I cannot have that. The good news was that he said because I was older than most people who get MS that it might be a milder form of MS. He felt the optic neuritis needed to be treated and that was why he wanted to admit me to have the steroids". **Mary, MS 4, Interview 2.**

"I remember in the room sitting there with my husband when the Consultant just came out with it, you know he was very matter of fact and he just said it. I remember saying well thank you very much and we left". **Amy, MS 1, Interview 1.**

"I had looked my MRI results up on the computer and saw that the marks in my brain were showing you some of the things it can be. And some symptoms with each and I said to my husband I have got MS and he said you might not have. So I went to the hospital thinking and feeling I have got MS and if I have not got it then even better. If I have then that is even worse mind. I went to see the Neurologist Consultant, I did not see him but I saw one of his men on his team. And he just said you have got MS and he did not even say multiple sclerosis actually, he just says you have got MS. So I went in feeling that so it was not too much of a shock when he said it. So I just kind of felt down for a few weeks and I just cried for ages". **Michelle, MS 2, Interview 1.**

"It was still a traumatic moment when I did have a diagnosis of MS and I am the same as everyone else I suppose with the fear of MS. The only difference was I had patients in my head who did have I knew as MS and thought I was going to end up like x, y and z and kind of thought the worst case scenario. I think I am a bit of a pessimist at heart so that did not help at all". **Professional 2 (who is also a person with MS).**

The Partners/Carers also had problems accepting the diagnosis and had feelings of helplessness, fear and anger in wondering what the future might bring.

“At that time of diagnosis I mean I can remember it so vividly, we came back home and we both sat here stunned and tears in our eyes and because I think within walls it's like most things you know what you anticipate is tomorrow there is going to be a wheelchair rolled in and you know your life's over and really we were just starting out. We're talking about what 18 year ago and we had 4 young children to care for”. **Mike, Partner, Interview 2.**

“I was really naïve and I just did not have a clue even though I had been a carer most of my life. I just did not have a clue because I had never heard, I had heard of MS, but I did not have any idea what was going on with it. It took over 6 years to be told it was RRMS. I was quite frustrated by it because he went through a bad time with countless snapping at everyone, frustrated anger and all the emotions that just came out and I was kind of getting it and I was just so naïve at the time because I just did not realise it was him like venting his anger out”. **Sarah, Partner Interview 1.**

“We were absolutely gutted obviously, and very bitter I was with a “Why Him” type of thing. But you have just got to accept it when push comes to shove, there is not a lot you can do about it”. **Nancy, Carer, Interview 3.**

The professionals also have to judge the best way to give the diagnosis on a patient by patient basis depending on what they feel the individual and their partner/carers can actually cope with at that time.

“Yes it is difficult telling people that they have MS, and that is why we err on the side of caution, by not telling them a lot at that point. Because you do not know what they want to know, at that point they do not know what they want to know, and it is only when they have gone home and spoken to other people with MS. Then they want to know will I get treated, what will happen, will I end up in a wheelchair, will I have to tell my employer and all those questions come after a bit and it is unfair to give them it all before they have had a chance to work out what they really want to know. But I would give a brief screed on MS and then listen to any questions they have then and get them answered and tend to give them some breathing space to go away and think about questions and then the MS nurses pick up in a couple of weeks encounter”. **Professional 3.**

“The referral will come from the consultant and we'll book them into our new diagnosis clinic. It might not even be new diagnosis it might be someone who has been diagnosed and gone off for a number of years because they've been relapse free. The clinics are an hour per patient so they get plenty of time to discuss either what MS is or literally just address the list of questions or requests that they've got. And a consultation could just be an educational content and judging on how much you think or ask the patient what they want to know. And it could be a more practical thing such as diet and nutrition, general insurance information, driving information or it could be more multi-disciplinary, when obviously they say that there is a problem with certain things that haven't been addressed, and then take them through the path of you know this is an alternative this is what they could do, physio, continence adviser, counsellor, social worker”. **Professional 4.**

“One would hope and I would hope that the relationship that I have got with patients who have got MS. I can think of maybe I have about five. So I have a couple that I have actually been involved in the diagnosis and the other 3 are patients with ongoing MS. One would hope that one has a good enough relationship with them that as you see them during crises when they need you that that you would empower, that it would be the GPs role to empower them, to help them by having a good consultation where you got shared decision-making. So this is what I think - how do you feel? What do you think would be the best next step? So you come up with a plan of action”. **Professional 1.**

The diagnosis period can be very traumatic especially if MS is something new to people and they do not know anything or have not heard about it. People have described the numbness they felt and how they wanted to get away from the situation and spend time with their partner and discuss it. Even when the diagnosis was known, suspected or a possibility the newly diagnosed people still expressed shock at actually hearing it and fears of what the future would and could bring. They all showed emotional reactions and felt the challenge of their own self-identity and loss of control. The loss of control was bringing emotional factors with the desire and need to regain control through the support of the partner/carer and having their family around them to make things as normal as possible.

Many people felt they did not receive enough information at this time, but they also thought they probably would not be able to take in any more, and responded by contacting the MSS and getting information from various sources. Others thought they had not received adequate advice or information at diagnosis and were left in limbo not knowing where to go or who to ask. According to Edwards et al. (2008) the diagnosis consultation and early treatment of MS, may influence patients' and their families' perceptions of MS, affecting adjustment to the illness. The discussions with the people with RRMS and their partners/carers suggested that the way in which they were diagnosed and how early treatment is managed may contribute to the longer term adjustment and thereby self-management and self-efficacy of their RRMS.

Challenge – self-identity: Telling people about MY MS

The people with MS and their partners/carers talked about breaking the news and telling people about the MS. They all recalled and talked about telling the diagnosis of MS to others and how they felt they needed to be strong and to protect people from their own devastation and disclosure. They talked about telling people who needed to know but not going public and wearing a banner or carrying a poster telling everyone that they had MS. Some people found disclosing their diagnosis painful and suffered loss of close friends who could not cope with it. Others found that they met and became friends with people they would never have met if they did not have MS.

“I was quite upset at the time and I didn't really want to speak much. That night I remember crying all the time and thinking well what am I crying for you know I'm being silly really. I remember just crying all the time. My husband was very supportive but

also totally, quite shocked you know and he was very quiet and really shocked and we did not want to tell anybody yet". **Mary, MS 4, Interview 1.**

"My husband was with me when I was told but he is so quiet it is hard to know what he is thinking but I think he was quite upset. My daughter got a book to read and all that, but at first she thought MS was Marks and Spencer's. I did not really talk much about it but the rest of the family, like my sister and that; she was like so you are alright then. So I said well no I have got MS and she said oh have you well and she and her daughter got really upset about. Because they were upset I was getting upset and then I thought why are they crying they have not got MS I have, what I have to live with it they do not have to. That is what was going through my head why do they want sympathy off me for. That was what I was thinking and I was just ignoring the way they were feeling but I do not know it was all so weird". **Michelle, MS 2, Interview 1.**

"It took me a long while to tell my best friend and I did not even tell my parents before that and I just wanted to keep it to myself. I was in total denial and I did not want anyone else to know, it was my secret". **Ian, MS 5, Interview 3.**

"I just felt that it was my job to hold everybody together (*said stressfully*) because they had to cope with what I had. Especially with my parents because at the time they were quite elderly and they did not really understand. But I felt on the initial stages I was the one who had to hold everybody together because they had to accept it and I had to try and understand a bit more of it". **Amy, MS 1, Interview 3.**

"I do not think they have actually come out and said anything to either my husband or myself. They just told us they are very sorry to hear about it and I think as far as my son is concerned they have been quite good back up to him". **Carer, Nancy, Interview 4.**

The telling of the diagnosis was selective to those who needed to know such as family and close friends and presented a real challenge to them. Some of the participants stated they would not withhold the information and would tell people if they asked or needed to know. Part of the journey and the acceptance of MS were through knowing that other people cared and supported them in coming to terms with the diagnosis. Internalised social constructions and expectations of others, led them to question their own self-worth.

Telling others the diagnosis is about making sense of the new "self" who has MS and people with MS may feel frightened, threatened or unsupported or subject to the risk of being ostracised or criticised. The person they married has a new dimension of their spouse to accept and for the children the parent may now be seen as being different. As MS is such an individual condition there is the uncertainty and unpredictability of what this means physically, socially, economically and psychologically for each person with MS. In telling their story the person with RRMS has continued their journey and in sharing this it may have therapeutic values or be part of the transitional process if the receiver is empathetic, caring and supportive. It gives the person with MS the chance to think

out loud which can help them to make sense of things, to discuss how they are going to cope and to focus on how they perceive their future.

Challenge – self-identity: What does this mean, what is it, how will I cope and be able to self-manage?

Following the actual diagnosis of RRMS was a difficult time in coming to terms with the future and what it meant for each of the research participants. Many of the participants did not know what MS was or what is meant to them but did wonder how they would cope and fit MS into their lives.

“The Consultant said well what I can tell you is, just straight out with it, you’ve got MS and I’m thinking MS what is that? I had no idea what it was, never heard of it at all and I thought will I be able to cope with that and carry on as normal”. **Amy, MS 1, Interview 1.**

“I was thinking at the time well what have I got and I was reading about everything to see what I did have. It really sticks in my mind when I think of the diagnosis of MS and it was what I felt I had not heard anything that they said at all. I felt really depressed in the early stages and could not believe that this was happening to me as there was no history and I did not know anybody with MS or even what it actually was. It was the tripping up all of the time that led me to think it might be MS because I was just falling over everything & walking into glass doors. I could see these things but I could not stop myself as the message was not getting from my brain to my body”. **Mary, MS 4, Interview 2.**

“It is hard, well it is not hard but it is difficult to accept what you can and cannot do so there are certain things that I have to think no hold on should I be doing this. I mean I can do most things but sometimes I have to think well if I do that I am going to have to pay for it over the next few days, so it is more the after effects on the MS that can stop me from doing some things. I try and recognise my limitations from the lessons of what I should do rather than what I want to do which can be annoying”. **Ian, MS 5, Interview 2.**

“Well my daily life has changed socially because I do not play rugby or do judo, I am not socially as active as I have said previously as much as I used to be, but it has not changed my self-identity. It is still me, but it is more that I just don’t walk as much and that I now do not drive. My physical difficulties stop me from doing the things I used to do in my daily life but my mental abilities are just as active as they always were if not even more active to compensate. I keep my mind very active I play chess, Sudoku and other mind games and I am daily accepting challenges in these areas and I am very confident with these. I am a confident person and am sure of myself and the MS or the challenges that is gives me do not deter me”. **David, MS 6, Interview 2.**

The partners/carers were trying to be very supportive and to help in the acceptance and coping with MS and being there for the people with RRMS.

“I do not think it has made any difference to her self-identity at all I have not seen much change in her, sometime she may be down but usually she is incredibly bouncy, confident and happy”. **Sam, Carer, Interview 3.**

“I had no idea what this thing MS was and because over the years he has been so tough and he was a lot tougher then. He did not want MS and he fought against it and everybody round him kind of got it in the neck. He was just kind of fighting all of the time because he did not want it and he did not want to be inflicted with MS”. **Sarah, Carer, Interview 2.**

“MS has changed his life completely in just about every way it could, you know. That is job-wise, balance-wise, sometimes the vision and I do not think he will ever get back to what he has been like prior to the MS and being comfortable with himself. But he has kept his sense of humour”. **Nancy, Carer, Interview 2.**

The fears of the impact of RRMS on quality of life and how the people with MS feel the illness may intrude on their life and their family, their social functioning and with their activities and interests can all have an impact on their self-identity. The experiences shared were described as touchstones for the interpretation and construction of events and situations which they felt at that time. As discussed above by Professional 3 the fears of disability and having visible symptoms which require support such as walking aids, mobility scooters and wheelchairs are things that they want to avoid for as long as they possibly can. This avoidance is one of the drivers for self-management with people taking risks rather than asking for help just to demonstrate their independence, coping and control.

“I think people with MS are more inclined to put themselves at risk to self-manage and maintain control even though they know about all the support out there. You can only suggest, and they can only take the advice, but I think a lot of people struggle with their own self management. I mean because of the risks around it. I did have a lady that has, that was diagnosed with MS for 32 years, and up to 3 years ago her diagnosis has changed to progressive MS. For that lady we had to pad the toilet system and everything because she chose to throw herself onto the toilet and the risks of that was to maintain her independence. So people do put themselves very much at risk because they do not want help”. **Professional 17.**

Some professionals discussed how initially MS may not have a full impact on the lives of newly diagnosed people with MS and they may not see them for years, but they were always interested in breakthroughs in treatments and potential cures.

“Young people are generally just coping, in general they do not have frequent relapses and they are just getting on with life. Some people have very little impact early on in their life with MS. Yes they tend to come in with newspaper clippings and downloads off the internet. We get a fair amount of that as people are looking more to their own management”. **Professional 3.**

“We as professionals sort of have that skill to realise that there are so many needs and the different coping strategies that different people have. And that we are not judgemental if they want to ignore it and we will support them in that. If they want information and knowledge we will support them in that as well”. **Professional 8.**

“You know you’re always going to have the odd one who will quite enjoy having their MS. You know they thrive on the fact that they are going to be looked after for the rest of their life. They may not necessarily be that disabled but they will play on it but we actually tell those people to get a grip you know”. **Professional 4.**

All three groups of participants in this research discussed the adaptation and having to move with the diagnosis as there was nothing that could be done to cure or stop the people with MS from having the illness. The important issues were symptom management and coping strategies and working together for plans and

hopes for the future. There may be people who do want to adopt a sick role and demand full support as suggested above and in these cases the partners/carers have also expressed feelings of powerlessness, fear and anger at these situations and find them hard to cope with. The data and discussions suggest that there is a strong link between coping and self-management which is supported by their self-efficacy including levels of confidence.

Challenge – Disavowal or Denial

Denial is an adaptive strategy which is multifaceted, a way of protecting oneself against events or feelings that cause distress and the normal defence of denial is often a process of disavowal. Denial can be a way of avoiding facing up to things; an illusion of control; pretence or avoidance; ways of minimising or rationalising; behavioural escape or suppressing the seriousness of something that is affecting oneself such as a serious disease or a LTC which has no cure or active treatment. With LTCs and cancers a certain level of denial is considered to be normal, and part of the unpredictable trajectory process that people go through on their illness journey, and could be part of the self-management, self-efficacy and coping mechanisms through the hiding of painful events and feelings.

Disavowal means that patients adopt dual thinking as their way of self-managing and coping with their diagnosis and prognosis. They appear to be able to have a rational discussion with professionals about their future, while at the same time maintaining a set of beliefs that appear irrational – a way of minimising the impact. They create a more bearable story of what is happening to them and move between the diagnosis and their own minimised version of events depending on what they can face at that particular time. All these coping mechanisms are normal, in the sense that they are part of a range of everyday defences against reality. People with challenging conditions change their perceptions over time, and need to come to terms with difficult information at their own pace and in their own way.

Most of the people with RRMS had some level of disavowal in terms of why me and what have I done to deserve this. Even those who stated they felt no denial were thought by their partners to be going through some elements of suppression or avoidance which were evident by their behaviour and adapting to having RRMS.

Some even question if the diagnosis could be correct stating that it cannot be right? Two of the people with RRMS had high levels of disavowal and concealment through secrecy and pretence, which are still present and go through the roller coaster of emotions at times. The reactions and adjustments to RRMS appeared to be elongated if there were high levels of denial as described by Amy (MS 1) and Ian (MS 5).

“It is denial though and it always has been in my head. I do have my head in the sand and feel as if I am like an ostrich and do not want to know what is happening. But well living with the diagnosis I have to live with it because I have not got a choice. It has always been there in the back of my mind, even though I have been going through denial and I still am and I have just had to cope with it in that way. The denial was a mixture of not believing what I had been told, but wanting the information to check it out and what other people had said to me about it not being very nice and this sort of thing. It was definitely refusal and I just kept saying that this cannot be me, it just can't be me. This then went on for a number of years and it is still with me to some degree”. **Amy, MS 1. Interview 8.**

“I was in denial until very recently and I have only come out in about the last year I think it is. I am totally out of denial now and I can see a clear line of when that actually passed but it did last a long time for about four and a half years since I was told”. **Ian, MS 5. Interview 1.**

“So things went back to how they were and I was still in denial and then I moved onto another Company and my mission to get closer to the North East but my illness remained my secret at all times. I was an engineer but I shied away from admitting my illness to my employers. This inadvertently had affects on my working performance. I was in professional denial until after I actually returned home. I did know that I had MS but it was still my secret. Now I am a much better person so I just wonder what the job was actually doing to me and how stupid I have been in the denial and not coming out with the diagnosis and the problems that I was having with the MS”. **Ian, MS 5. Interview 8.**

Two of the people with RRMS had previous experience of people with MS and appeared to accept the diagnosis more easily. They felt they did not have any denial which could be because they were modelling themselves on people they knew with MS. They knew what it was and stated:

“There is no point in having denial because you just have to get with things – it is not going to go away”. **Richard, MS 3, Interview 1.**

“I was never in denial and I knew I had it and I had known it for a while before it was confirmed and there was no use in denying it at all. I had such a long journey to get to my diagnosis so it was a relief to find out that they had found something and knowing that there was actually something happening rather than me and them thinking I was a hypochondriac”. **Michelle, MS 2, Interview 1.**

The other two people with RRMS did question “Why Me?” when they had a good life, were good people and tried to look at reasons why they had been inflicted or invaded by MS. They both quickly realised that they would have to accept MS, learn to live with it and not let it take over their lives through their own adaption and coping mechanisms.

"Well for the first year I must have cried every day for a whole year and I could not accept it and it was always well "Why Me" you know. I do not really say why is it me now, but I did at first and I thought why me what have I done to deserve this, and then I used to think for ages have I done something really bad and is this God's way of coming back to me and I could not see that I had as I was not wicked or anything. I cope but better now with my emotions than I did in the early stages but I think things became better after I started to accept the MS and learn to live with it and not let it take over". **Mary, MS 4, Interview 3.**

"I do sometimes think why me and what have I done to have this invade my body. When I was in top form with my judo I felt I was unbeatable and my body was at peak fitness but now I know I will never be like that again so I have to accept it and move on and not let it take over my life". **David, MS 6, Interview 2.**

The Partners/Carers talked more about the effects on the family and their own lack of understanding of MS and how if they knew more about it they would have been more supportive. One carer whose partner stated they had denial of MS felt that there was not denial but just slow acceptance and getting on with things. The different levels of perception seemed to relate to how they reacted and adjusted to the diagnosis which would not have been explored if all of the interviews were undertaken jointly.

"Initially when he was in denial and he would not accept the diagnosis he would not engage at all. He just was not interested and he did not believe he had MS. He would not talk about it at all – not with me or the family and certainly not with the professionals. He just used to sit and let them talk and would not ask anything and just agreed with them and wanted to get out from his consultations. We went through a dreadful time when he was really down and he was moody and always snapping at me and the children. I thought we cannot go on like this; we had not been together that long and I was really worried about the effects on the family". **Sarah, Carer, Interview 4.**

"It was really hard going through the denial period and being kept on the outside but he seemed to be okay and he came through that. But it is something that I still find quite hard to get my head around it, because he was such a good actor he covered up well. I think also in that respect that he told his sister more than he told us and we felt a bit left out. We have always been really close and that made it really hard and it was not something I would like to go through again. We never really got any reasoning for it and it was just his way of dealing with it at the time". **Nancy, Carer, Interview 4.**

"I think we do both accept MS and in a positive way and we still have the denial at times and you get over that because my wife does not want to feel sorry for herself and I do not want to feel sorry for her. Yes because she is so head strong, even to the point of total denial, it is still in the back of her head but she tries and not let it bother her to the point that it effects what she does. It was really strong initially and it has tapered off at times but it is still there and comes over very strongly when things happen and action is not taken quickly enough". **Sam, Carer, Interview 3.**

Specific reactions and adjustments to knowing they had RRMS

The clearly specified reactions and adjustments to RRMS reflected upon the variability and uncertainty of the illness and not knowing day to day how things would be. The people with RRMS in this study faced significant changes in their social and familial relationships and life roles while dealing with psychological

distress, physical pain, prolonged medical treatment and gradually increasing interference in or restrictions to the performance of life activities. They knew life without RRMS and had learned what was socially accepted and expected, and were aware that others undervalued people who did not conform to cultural expectations. However, they did not seem to allow this to stop the planning of things or prevent them from trying to do things as best they could. This positive outlook, self-determination, self-control, self-efficacy and integration coming through from the grounded data may be unique to RRMS and could be an area for future research.

“I take it as it comes. If I wake up one day and I am not feeling as good and I am not able to move as good obviously you’ve not predicted that well you just have to cope with it. If you’re having a down day you’re having a down day you know you have got to live with that. Instead of getting out and physically doing something, I sit down and read a book. So I change my activities and what I want to do according to how you feel”. **David, MS 6, Interview 2.**

“MS takes control of everything like I cannot go shopping and wandering off all of the time and I cannot really walk anyway. We used to walk for miles and uphill went walking all of the time especially when the children were young we were always out walking. We were always out and never in the house but I cannot really join in anything now. I think things are gradually getting worse over the years but that could be age as well and not just MS”. **Mary, MS 4, Interview 3.**

“We work together and I am the calmer of us both and try to take things in my stride more and try not to get uptight. We cannot take MS away, it is not treatable but along the way we can be positive, we can be happy and live with it, at the end of the day we can live with it and cope. She is very aware of the way people look at her now and tried to avoid contact as she wants them to think of her as she was before MS”. **Sam, Carer, Interview 3.**

The psychosocial reactions and adaptations that people were going through were the initial shock and anxiety, denial or disavowal, depression, anger and insecurity (bitterness, resentment, guilt and self-blame), aggressiveness, helplessness, uncertainty, hostility (retaliation against physical limitations). Social; isolation, acceptance (future implications); positive feelings and attitude (needing to feel and be positive to stop MS taking over); and final adjustment (emotional and behaviour acceptance and realisation that they have to get on with things. It is not going to ‘go away.’ The biopsychosocial model (discussed in Chapter two) can support the psychosocial adaptations by responding to the functional, psychological and social changes that occur with the onset and experience of living with RRMS and its associated treatments. These require multidimensional responses and processes that are unique to individual needs. There were fears expressed about the future with worries about physical limitations, uncertainty and even fear of death being generated from the data. These were manifested in different ways across the six

people with RRMS and the partners/carers who described how they helped and supported them during this time.

“An awful lot of frustration and of course the nearest and dearest get it which is really unfair because they do not deserve it. I have to vent my frustration somewhere and if it is not my husband it is the dog and that is just not me taking it out on them. But that is just the way it is at the moment pretty nasty but I just cannot control it”. **Amy, MS 1, Interview 4.**

“My boss was concerned about me and I was concerned about not being able to do the job and not being able to get the work done. I was getting frustrated, hostile and angry with that and she was getting worked up because she was worried about me. We sort of had a bit of a chat but since I’ve been diagnosed I’ve taken some information leaflets into work and they have been absolutely fantastic. They’ve been more supportive, they changed my hours, they’ve changed my job, and you know they’ve really adapted to my sort of problems”. **Richard, MS 3, Interview 2.**

“Well I have got a strong positive mind and I think I did not just accept it, I did not say to myself well this is the inevitable, you know. You do what you do on the day and if there is something that you cannot do today which you could do yesterday that is hard lines. In my mind I am not giving in to it, you know it is just the body cannot do what my mind wants, there is nothing wrong with what goes on in the top here, things do not react to it”. **David, MS 6, Interview 3.**

“I felt numb at the time but I felt well we just have to get on with it and you cannot let the MS control your life. We just give her the support she needs and work things through together to make the best of things”. **Denis, Carer, Interview 2.**

The professionals are available at this time and willing to provide the support that is needed when requested and to make referrals to the appropriate teams.

“We try to encourage them to come to terms with their feelings and to be as independent and positive as possible. We provide the therapy support to help them and to maintain their confidence. The multidisciplinary team aims it to provide the one-stop service to empower the patients through pulling together the advice and support they require to help them build up the confidence and control their visits”. **Professional 5.**

The onset and diagnosis of RRMS has been a very challenging and emotional time for the people with the illness and their partners/carers. As shown above the ways that they coped with it and supported each other were different in terms of the reactions to believing and accepting the diagnosis.

Engagement with Professionals

The engagement process with professional carers at this time was variable due to the different levels of denial or disavowal and the fact that most people wanted to come to terms with the diagnosis prior to learning more about MS. Quotes used here came from the stories and interpretation of the people with RRMS and their partners/carers as they shared them with the researcher. Some people can only tell their stories long after experiencing them, and for some of the people involved that

was many years ago, but they stated repeatedly it was so clear in their minds. These quotes reveal their interactive interpretation and construction of their stories, offering description of what remained unsaid, and showing its significance by enhancing its presentation through the symbols they used. These quotes have been co-constructed with the professionals' perspectives. The importance of acceptance, adjustments and reactions to accommodate RRMS have been stressed throughout this chapter, which may suggest that the early days of living with RRMS, may have an impact on the engagement process with the professionals and the willingness to self-manage and feel confident in terms of self-efficacy.

Theoretical Linkages: The Trajectory Framework

In this research a RRMS trajectory framework was developed within grounded theory through utilisation of interpretation, constructionism and symbolic interactionism. The research participants told their own stories, as a contribution to knowledge, in specific areas which assisted in their own understanding and in the management of their MS. The trajectory framework initially developed by Corbin & Strauss (1988, 1992) using grounded theory techniques to design the LTCs trajectory, which evolved during 30 years of research and observation of practice. The original purpose of the trajectory framework was to gain greater understanding of what it is like to live with, cope with, and manage a LTC. The LTCs framework, as a grounded theory, was developed from an extensive research programme on dying, and was refined in studies that included a range of settings and patient groups. The central concept of the framework is a trajectory, or illness course where work is undertaken by individuals in three main areas: managing illness work (regimes); biographical work (coming to terms); and everyday life work (limitations management). Corbin brought to the framework the expertise and management of chronic illnesses with the long term nature of the conditions and the uncertainty and unpredictability that have an impact on the normalisation of activities and lives of the patient, their family and professionals involved in the management and support of their diseases. According to Smeltzer (1991) the trajectory framework is based on the premise that LTCs have a course that varies and changes over time, and that the illness course can be shaped and managed even if the course of the disease itself cannot be modified.

Corbin (1988) viewed the trajectory as embodying a sociological perspective on events that are ordinarily and primarily interpreted in medical terms or a combination of medical and psychological terms. She refers to the changed relationship of the body, self, and sense of biological time. In some measure the body is now failed or failing and this is affecting one's social performances and perhaps one's appearance. This description supports one of the major themes in this research with the challenge of self-identity. Corbin (1988) refers to the contextualising of the illness, coming to terms, reconstituting biography, respectively with each of these processes requiring a great deal of biographical work.

For the people with the LTCs this can represent a cumulative effect of physical and psychological limitations which impact on the person's social world challenging their perceptions of self-identity. The self refers to how people feel about themselves and their identity is shaped by how they feel that others perceive them externally or through social interactions. According to the seminal work of Mead (1934) communication entails cooperative activity with others and is the basis of shared significant symbols which give meaning to what one feels, sees, hears, smells and touches. The body itself is one of these significant symbols which can become an object which is distinct in all of its parts yet integrated into a whole. In using the body one engages in activities and tasks during which times concepts of self are formed and reformed. When a person is not able to perform the activities and tasks that they have always done this can make them more self-conscious and open to criticism which can have an impact on the self. The challenge of self-identity has been discussed in this chapter and the impact and changes of RRMS on the person with the illness and their families and professionals that in turn affect the self-management and self-efficacy of the illness itself. Charmaz (1983, 1987, 1999) stated that the people with LTCs experience physiological symptoms but also disruption in work and family relationships and future plans, which can lead to a loss of self. She states that people with LTCs frequently experience a crumbling away of their former positive self-images which are often no longer available to them.

Based on the uncertainty and unpredictability of RRMS it would be easier to plot the journey of the trajectory retrospectively, but based on knowledge, values,

beliefs and experiences of patients and professionals it is possible to provide a prospective view (Thorne & Robinson 1988). This is similar to the MS journey map produced by the researcher from areas raised in the literature review (see Diagram 4.2) and has been shared with the people with RRMS and their partners/carers and the professionals. The drawings of the maps of the people with RRMS around their own personal journeys which were undertaken in interview eight are in Appendix VI.

The trajectory framework describes eight mutually exclusive phases that move from pre-diagnosis (occurs prior to the onset of the disease), trajectory onset (signs and symptoms first appear), crisis (requires emergency care), acute (associated with hospitalisation), stable (inactive disease causing changes in abilities), unstable symptoms (out of control), downward (symptoms causing decline in functional capacity) and dying (terminally ill). In RRMS where there is no cure the use of the trajectory framework encourages the professionals to consider the person with RRMS holistically with full consideration to the person's, their partner /carer and family's critical roles in the management, coping strategies and self-management to maintain independence and self-efficacy. This may help the individual, their family and professionals to plan for the future and cope with RRMS through the unique unpredictability, varying courses of uncertainty and the symptoms of RRMS. The trajectory projections including goals and target settings can influence the interventions and attitudes which can help to motivate people with RRMS and their partners/carers and professionals to take action when symptoms appear or additional problems develop.

The five steps of the trajectory framework used by Corbin & Strauss (1985) have been applied to RRMS by Smeltzer (1991) whose impact demonstrates family centred and social support requirements. These five steps have been further modified by me in line with my research:

Step 1: Locating the Person with RRMS and Family and Setting Goals addresses Corbin & Strauss's three lines of work which are illness work, everyday life work and biography and examines the interactive effects among them. MS requires a continuous state of modification and revision through the relapses and remissions that impact on their life and lifestyle.

Step 2: Assessing RRMS Influencing Self-Management identifies factors that facilitate or interfere with the self-management of the trajectory and achievement of goals and targets which can be supported by resources and modifications through professional and social support.

Step 3: Defining the Intervention Focus defines the target of intervention to determine what should be manipulated or modified to enable reaching desired goals and targets.

Step 4: Intervention is about shaping the journey of RRMS and preventing complications while promoting and maintaining quality of life through supportive assistance and maintaining independence.

Step 5: Evaluating the Effectiveness through the development of self-efficacy the effects of the goals, targets and interventions supported the management of the prevention of complication, an acceptable quality of life, maintenance of self-control and independence.

The phases and steps of the RRMS trajectory do not represent a rigid framework for the linear consideration of a patient's response to MS as each person illness is very individual. Hence the roller coaster ride where movement along the trajectory can be in either direction and can rise and fall with the dynamism reflecting the continual nature of adaptation that characterises the MS journey. Problems can arise at each stage of the trajectory, where varying management strategies are introduced to maintain coping, self-esteem and confidence levels. Corbin (1988) states that any trajectory can be analytically broken down into phases, which provide the shape of the stages which are described as the roller coaster ride within this research study. The phases are acute, comeback, stable, unstable and downward and correspond to the physical and physiological status of illness. The trajectory concept is useful in making sense of the stages of LTCs such as RRMS. The goal of understanding and knowing about the phases of trajectory management is to provide support in order to maintain an optimal quality of life for the person with RRMS.

The roller coaster of RRMS.

The roller coaster of MS is a complicated journey of ups, loops, stasis, bends and downs. The journey of MS in this research was described as confusing, and the pathway is often lonely and challenging, with paths that are convoluted,

interrupted, delayed or reliant upon responses from others. Confusion and losing direction is not uncommon with periods of stillness and an increase in bends and loops at times, which provides the challenge of wanting to stop it and return to “normal” and take control back. Many voices are heard along the route with different opinions, understandings and options; while the person with RRMS may be embarrassed, self-conscious or trying to hide their visible symptoms. Losing direction and confusion is not uncommon as the ride continues or there is an increase in loops or possibly relapses. The roller coaster does not appear to have an end but the journey continues with a turbulent route across the MS trajectory. Seeing others with MS along the way can sometimes be helpful to see how they are doing, to compare their symptoms and ways of coping and making comparisons. Once they realise they are living on a rollercoaster there seems to be a turning point in the challenge of RRMS.

The early and ongoing symptoms of MS like the roller coaster are like altered sensations, fluctuating, uncertainty, variable, unpredictable and convoluted. Listening to the voices of the research participants will expand the themes and take us along their own MS journeys. En route the people are wondering what is wrong with them and beginning to challenge their own self and how others may be seeing their own symptoms and what is their own self-identity. By conception of the challenge of self, I do not merely mean self-esteem (how one feels about oneself), but rather the views held by oneself in relationships to the whole identity of whom one actually is. As Corbin (1988) states these views evolve in accordance with an ability to perform the tasks associated with various aspects of self. Such views are often expressed in metaphorical terms by the ill to describe impacts that illnesses have had on their lives.

The challenges of being diagnosed and living with RRMS affect each person and their families across their lifetime. The learning that they have MS is often made harder due to the young age at which people are diagnosed which is typically between the ages of 20 and 40 years when they are starting relationships, their career and families and are usually starting to be independent. By this time they have generally established their identity as a person without a disability or LTC; when they then have to think about who they are, what RRMS will mean to them and the impact it might have on their future. Then as people with MS do not

generally have a reduced life expectancy, means that they have to live with the disabling effects of the illness as well as the typical physical and social changes which are associated with ageing. The challenges of RRMS are very prominent in the early stages but do run throughout their lives on their continual roller coaster ride.

The locus of control involves the individual's perceptions of control over reinforcements and reflects the belief in the ability to manipulate environmental conditions affecting the individual (Martz et al. 2000). Goodrich & Fullerton (1985) describe internal locus of control as a perception that the reinforcements or rewards, which individuals experienced, depended upon their own actions, characteristics, or skills. In contrast, individuals with an external locus of control believed that the reinforcements or rewards following their actions were not related to their choices but were controlled by external agents (Friedman et al. 1985). This research has further demonstrated (see Chapter nine) that locus of control may be related to individual's coping behaviours.

Conclusions

This chapter was about understanding the early experiences and listening to the voices of the people with RRMS, their partners/carers and the health and social carers. The research endeavoured to explore and share how quickly the lives of those with RRMS changed through feeling unwell with bizarre symptoms, being swept along with a diagnosis, while going through the turbulent passage of reality through the roller coaster of emotions. They all reflected on the day of diagnosis and the challenge that brought in terms of feeling lost and loss of self and questioning their own identity and how others might see them. They all went through some stages of the challenge of denial/disavowal and coming to terms with the reactions and adjustments that RRMS brought to them. There were experiences of uncertainty and not knowing what MS means and how they would cope with true fear of the unknown.

I found myself located within the research process and seeing the feelings, words and silences coming alive through working with these people over eight months. I was given the opportunity to journey with them through their MS trajectory sharing the situations they faced, their memories and challenges of their lives in the early

days of living with RRMS. The next chapter will move onto the next stage of the journey moving through the transitional period as they moved back and forward on the roller coaster ride in what the participants' described as coming to terms with living, accommodating and coping with RRMS.

Chapter Seven: Transition

RESEARCH FINDINGS

Central Theme – MS Journey Roller Coaster – A turbulent passage of reality
Major Themes – Challenge, Transition and Transformation.

SUB THEMES	CHAPTER SIX: MAJOR THEME- CHALLENGE
Losing control of self-identity	<ul style="list-style-type: none"> Feeling unwell en route to diagnosis Reflecting on the diagnosis day What is MS? How will I cope?
Denial or Disavowal of RRMS	<ul style="list-style-type: none"> Why me? What have I done to deserve this? It cannot be right Reactions and readjustments

SUB THEMES	CHAPTER SEVEN: MAJOR THEME – TRANSITION
Engagement in the process through taking more control	<ul style="list-style-type: none"> How quickly life changes – the illness transition? Visible and invisible symptoms Unpredictability & uncertainty Feeling in control and using own power
Ability and willingness to self-manage to accommodate RRMS	<ul style="list-style-type: none"> Learning to live with RRMS Self-care, coping and motivation Ability and willingness to self-manage Staff need to listen to what is being said and respect autonomy

SUB THEMES	CHAPTER EIGHT: MAJOR THEME – TRANSFORMATION
Accepting the intrusion of RRMS and regaining control	<ul style="list-style-type: none"> Empowerment, encouragement & support Self-efficacy and determination MY life changes & transformation & making the most of it
Embracing RRMS and moving on and making the most of life	<ul style="list-style-type: none"> Reclaiming life 'I have MS but it does not have me' Working in partnership with my own choices and decisions Vision for the future – making the most of life

Introduction

The second chapter of the research findings describes the transitional phases of the RRMS trajectory which is when the people with MS and their partners/carers started to move towards incorporating and accommodating RRMS into their lives. These are not discrete linear phases, due to the uncertainty and unpredictability that MS brings, intruding from the constant movement of the roller coaster into learning to ride it in order to maintain their self-efficacy, self-manage the turbulence, instability and further challenges to their lives. This results in moving backwards and forwards across the phases in different levels of acceptance, adjustments and disavowal. This chapter describes the views of unpredictability and uncertainty and how the engagement process influences self-management and self-efficacy. In order to illuminate the nature of the research participants' experiences their quotations will lead the discussions with the theoretical linkages appearing after each section and summarised at the end of each chapter.

In this research the transition occurred due to the positive nature of the people with RRMS with their self-determination, self-efficacy and independence striving to self-manage along with the support of their families. The challenge of feeling unwell and being diagnosed with RRMS, with no cure or effective recovery treatment, can make people and their families feel vulnerable as they go through the illness experience, symptoms and rehabilitation therapies. The people with RRMS and their partners/carers did recognise the transition they were going through and these experiences will be shared with the reader throughout this chapter. Here are two examples the first looks at the awareness related to perception and knowledge, health relationships, support and moving on to self-management; and the second the role and social relationships of care giving, self-efficacy, change and self-management.

“When I was first diagnosed I had all these people coming at me, physios, fatigue specialists, doctors, nurses, the MS Specialists, the MS nurses you know with appointments. Then all of a sudden because I have had a steady transition through the condition, and no major relapses, all that seems to have died off and I seem to be having just regular check-ups which to me is better, as I would rather just do that than keep having to go and see everybody on a regular basis. I think it is best, for me to continue with my life as normal as possible by self-managing, and just carrying on”.

Richard, MS 3, Interview 2.

“Although I was diagnosed with MS I felt that it was a big relief that it wasn’t anything life threatening but something I could self-manage with self-control. Strange but my wife and I have been together for over twenty years now and we both supported each other over that time and she’s been a great support to me with the MS. She’s sort of put her life on hold through the transition of role reversal where she was working part time and I was working full time, now it’s the opposite way round she works full time and I work part time”. **Richard, MS 3, Interview 2.**

Learning to live with the constant changes facilitated the transition of acceptance and accommodation of RRMS. People need time, space and resilience to adapt and cope with the changes to their lives as the move through the transition of reorientation and redefinition to gain confidence, coping mechanisms and maintain their self-esteem. Acceptance of the diagnosis was integrating MS into their lives and going through the transition of claiming the diagnosis and becoming refocused and trying to get on with their lives. They accommodated the fact that MS does not kill you, but that you have to learn to live with the physical limitations and cognitive issues.

Accepting a diagnosis of RRMS can lead initially to a feeling of personal loss, devalued sense of self and changes in self-identity. This change in having RRMS in some people can cause a shift from seeing oneself as healthy to seeing oneself

as having MS which in some ways brings a fluid and integrative identity. It was described as being like having bereavement with a person mourning for the loss of their health and active life.

“Well for the first year I must have cried every day for a whole year and I could not accept it and it was always well “Why Me” you know. I just could not stop crying and I would lock myself in the bathroom and just cry for ages and then just cry every night in bed you know because I felt my life is over really and it is like bereavement and you cannot do what you want to do any more”. **Mary, MS 4, Interview 4.**

The emotional reaction to RRMS is part of the adjustment process where people go through adaptation, adjustment, acceptance and integration. Le Maistre (1985) stated that the stages are similar to the emotional process of grieving going through crisis, isolation, anger, reconstruction, intermittent depression and lingering depression which can be repeated as the illness recurs and other losses are incurred. It can also be described with the roller coaster metaphor with an upward spiral where coping mechanisms learned at one time can be combined with strategies learned at another time so that each bout of illness causes less upheaval in one's emotions.

Engagement in transitions

The level of engagement is a property of transitions which is defined as the degree to which a person demonstrates involvement in the processes inherent in the transition and makes changes accordingly. People may go through more than one transition at any given time where recognition is important as lack of awareness may influence the level of engagement (Melesis et al. 2000). This includes seeking out information, setting goals and targets, being involved in the care management process, actively preparing and proactively modifying activities which are all coming through the data generation within this research study. The level of engagement of a person of their physical, emotional, social and environmental changes is influenced by their awareness of their RRMS and wanting to be involved and an active participant in decision-making, their own care processes, health promotion and lifestyles. There are different types and levels of engagement in the transition and at times some people chose not to engage but prefer and choose to be more of an inactive or passive recipient in their care. An example here was during a transition where the symptom treatment was not working due to building up antibodies to the drug and she had four months with no treatment at all.

Amy, MS 1 decided to take an inactive part in the consultation process to allow maximum time for the Consultant to decide on the new treatment.

“I was so desperate, so agitated and so worked up to see him as my life was on hold and my future was in his hands. That I could not think about what I thought of previously and what I should have asked him so I tried to stay quiet this time by not saying much at all. I let him speak and tell me what he was planning to do because I really just hoped he would do something and I was going to plead with him to do something but I knew he had something in his mind. I could sense there was something and I was desperate for something to happen and to start new treatment”. **Amy, MS 1, Interview 2.**

Amy was very aware of this transitional time when she expressed feeling unwell, feeling vulnerable, experiencing increased uncertainty and her mobility was limiting her lifestyle, self-efficacy, and fear for her future and self-management. She had previously talked about the importance of being involved with the professionals and working in partnership with them but here her desperation for change to make a difference in a timely way to her symptoms was a critical point and this consultation was an important event for her.

With people with RRMS this needs to be explored further as there are times when they do reach success, but by the very nature of the condition with relapses and remissions, there are times when they reach it and times when they feel it is swept away from them through the up and down turbulence but then bounce back. The distinctive dynamic process of resilience in this research was demonstrated within the data generation through the people with RRMS maintaining positiveness with self-determination from the turbulent passage of RRMS as one of the clear drivers to engaging with self-management and self-efficacy. During the turbulent transitional passage in the reality of RRMS the journey will next move on to discuss the unpredictability and uncertainty as described by the research participants.

Uncertainty and unpredictability

In any LTC there is some element of uncertainty and unpredictability across the trajectory regarding the causation, diagnosis, prognosis and individual requirements, which impact on service provision and professional support. Uncertainty and unpredictability are multifaceted and over the trajectory of RRMS and cannot be removed or reduced but people have to accept and manage the knowledge of limitations within the process framework which is shared between people with MS, their partners/carers and professionals. The explicit recognition of uncertainty and unpredictability by professionals can help them to provide support

to the patients and their partners over their trajectory. These variables in someone's life that cannot be controlled or even predicted, make them stressful and difficult to deal with. The loss of physical movement, incontinence and cognitive functioning can be very distressing.

People do not know in the short-term when the next relapse or exacerbation will occur, what will happen to them, how long it will last, if they will recover, or what it will prevent them from doing. This makes it difficult to plan ahead and is therefore a constant worry. Also, looking further into the future, people are not able to predict the course of their condition. They do not know whether they will continue to work, how they would cope financially without working, whether they will remain mobile and independent or will become more inactive and may even feel a burden on their families. MS forces people to consider these possibilities, through the limited ways in which they can, in order to control the outcomes.

These issues must be faced by an individual with RRMS, not just once following diagnosis, but continually throughout life. RRMS is variable, uncertain and unpredictable but is usually progressive within an individual time frame as it is a very individual illness. Lives will constantly have to be changed and adapted to allow for the limitations imposed by the condition. Individuals may have to consider accepting physical aids, such as a walking-stick, four-wheeler walking frame or wheel-chair, in order for them to continue being mobile, they may have to become reliant upon those around them and accept changes in their life role. Partners/carers tended to focus on current needs with fears and anxieties for the future trajectory which caused tensions when trying to concentrate on coping strategies. Professionals found it difficult to share their interpretations of the trajectory tending to focus on their own interpretation which was related to their own area of expertise with difficulties in predictions and understandings.

Some people do not want to adjust their lifestyle to accommodate their physical limitations and feel they lose their self-identity if they have to use mobility aids. Some refuse to use a walking-stick, preferring to stagger around and let people assume they 'may be drunk', whereas others will attempt impossible tasks to try to prove to themselves that they are still 'normal'. As discussed here by Michelle, MS 2:

“Sometimes I stagger around and my walking is not great and people think I am drunk, but I would rather have that than used the sticks. Recently my walking has not been good at all and I have had to use my sticks so that I can go slower and take my time, because I tend to walk fast but my leg has been really hurting. I am more than aware of my MS and other problems, I know I said that I was normal then and I do know that I am normal now. But I have got lots of things wrong with me but I will not change what I do and refuse to use a walker and I will never use a wheelchair ”. **Michelle, MS 2, Interview 5.**

Their RRMS may become more visible to others, which they feel will create further changes in other people's perceptions of them, and how they treat them. Each person copes with their physical limitations differently and they personally need to decide if and when they need support and what that level of support is. Hiding parts of the body or not using mobility aids was seen as important to maintaining their own self-esteem. Professionals and partners/carers can make suggestions and discuss the mobility aids that are available and how these may help but the end decision must come from the person with RRMS themselves.

“You and the symptoms are unpredictable and sometimes you are uncertain from day to day as to what you face. It is a nature of the MS and the disease”. **Richard, MS 3, Interview 2.**

“The Rebif did seem to help me to cope with the unpredictability and uncertainty of my MS because I was getting fewer symptoms and what I now know were relapses. Sometimes I do have a short fuse and feel I am living on the edge with the uncertainty and the unpredictability, as you do not know what to expect. Other times I just let things wash over me and do not want to know”. **Amy, MS 1, Interview 4.**

“I do not cope with uncertainty and unpredictability because I always think well why has it got to be today and I do not like it having control over things. It is just the luck of the draw when things occur sometimes if I am going to go somewhere or plan something I think I hope I am going to feel alright”. **Mary, MS 4, Interview 5.**

The partners/carers also shared their views on how they felt the person with RRMS was coping with the unpredictability and uncertainty and the kind of effects it was having on the family.

“I think the adaptability, unpredictability and uncertainty still preys very heavily you know you get a twinge and she thinks oh no not that again where is this going. She uses me as the springboard to change things and chase them up. So the unpredictability bit is waiting for the next twinge and trying to work out which it is and what the impact will be on the MS and I think that is knowledge as well. The uncertainty does sometimes get to her as she feels things are going along smoothly but when her mobility is not as good as it was, then she is thinking what next and she needs to be able to get around and continue to do everything for herself”. **Mike, Carer, Interview 5.**

“We have both learned that there is no point in worrying as you cannot control how MS progresses. It is so different for each individual and impossible to predict. We just take each day as it comes and deal with it accordingly. The professionals need to listen to people with MS and know what it is like to be messed around like this. To cope with uncertainty and unpredictability and when you are trying to get things sorted to make life more bearable to listen and act”. **Sarah, Carer, Interview 6.**

"It is so unpredictable and can be uncertain from minute to minute, as it now seems to be that all of a sudden she has got to the top of the ski-slope, and she is now in top gear because things have gone downhill so dramatically. It is really hard to project anyway it is an unbelievable disease that affects so many people in so many different ways and you just do not know how it is going to hit". **Sam, Carer, Interview 4.**

Within the professional focus group there was a conversation regarding support and coping with the unpredictability and uncertainty for people with RRMS and their partners/carers; and it flowed like this:

"I think one way for supporting the unpredictability and uncertainty is when you are in a particular period of someone's illness and discussing the current problems, trying anticipating the problems with somebody and saying this is what we can do now but we need to have a contingency plan for your next relapse or whatever. But you are limited as you can only go as far as the person wants to look you know I think there are limitations". **Professional 15.**

"Some people do not want to look that far ahead, some are quite happy to go from one crisis to another as long as they have got support". **Professional 16.**

"I am not sure I would like somebody trying to tell me what my life is going to be like 20 years from now. So I can understand that but sometimes I wish they would think and plan ahead more". **Professional 15.**

"I think we can support them in the here and now and be responsive so that when they have relapses and crisis that you are able to respond and that we have the resources to do that". **Professional 11.**

"I think it is about people needing to have the confidence of knowing that if they do have a crisis they know where to get that help". **Professional 16.**

"It is about being aware of what resources are out there and how to access them; it is about seamless working with educational support". **Professional 9.**

"I think again it is very much individualised care and working with the people with MS and their partner/carers to help them cope with the uncertainty as things develop and to provide the support as and when they need it. MS is so difficult and it is not possible to predict what will happen to whom and it is very much about working with them and keeping them active and able to do what they see as being important to them". **Professional 5.**

The fear of the unpredictability and uncertainty seemed to be around developing new symptoms and progression of the RRMS as the prognosis is uncertain for each individual. Much time and energy is put into managing fear at all phases of the MS Trajectory and many of them used this through the engagement with information and knowledge about the symptoms and understanding RRMS better. They knew or could work out the causes of their symptoms but the future was still unpredictable and living with RRMS felt like an uncertain future. Most of them had resigned themselves to take a day at a time and to cope with things as and when they came and to make the best out of their life. They all recognised the importance of engaging with professionals during the periods of uncertainty and unpredictability to seek the support for them to enable self-management and

improvement of their self-efficacy through developing coping mechanisms for the current and future phases. It appeared that they had fluctuating patterns of engagement in order to regain their self-sufficiency.

Self-care, coping mechanisms and motivation

In order to explore the concept of self-care, the Department of Health's definition was read out to all the research participants for their reactions. The six people with RRMS and their partners/carers in this study have expressed recognition in the importance of the role they play in managing their own health, they state they are confident in fulfilling that role and willing to engage with the formal carers to support them in self caring.

"I totally agree with the definition of self care and I mean it is up to every individual to take responsibility for themselves and I think they should do. If people want to be any better they need to control their health with exercise, diet, use of medicines and things like that, I believe that I do that and do try to stay in control and be fit and healthy. People with MS should look after themselves and self-manage and be in control as much as they can. We need to have support and information from the professionals as and when we need it to help us". **Amy, MS 1, Interview 3.**

"It is always a concern for me that those kidney problems will come back and the last time I went to the GP and I saw the nurse and she tested my urine. Then said that it was touch and go and to come back in 2 weeks. I went back in 2 weeks and she said that everything was clear and that I was fine. I have asked her repeatedly for testing sticks to test my own urine but they seem to be reluctant to give them to me and that is the only way I can self-care and make sure I do not have urine infections. At least then I would know if I had a problem and could see if I needed any treatment or not. I do not understand why they refuse to let me be involved in my own self care. I have looked after myself really well for over 20 years with RRMS and I have self-managed and got on with life and I do not want something like this to knock me off my feet. I really must get it sorted to stop things becoming severe". **Mary, MS 4, Interview 5.**

A couple of things really within that self care definition and it is a very big thing to have to do it all yourself in many ways. Much of it contains things that I have thought of a lot myself and I can do most things myself and I try to keep myself fit and active. I am mentally sound across the disease itself and that is still how you do things I do try and do memory test things like that but you can do all you can but sometimes the cognitive issues are beyond your control. In terms of being positive and determined and I feel like that and want to continue to be in control but I do not feel that the definition is very clear in those areas". **Ian, MS 5, Interview 5.**

"I think there are people who will fit against that self-care definition no problem at all and will be well suited to that because they will pursue their good health, their wellbeing and make changes. There are those who will fail to even recognise that they have MS even after diagnosis that would not be happy with that because even with the challenges that they have got it is about the DH. There are those who only respond to an invitation from the Neurologist or the Doctor or whoever. There are two distinct bands of people there are those who will pursue and have no difficulties in meeting the guidelines and the government perception of what people should be taking on board. But there is the other perspective where there is failure of people to even recognise their condition and they sit back, dwell, not participate or engage with any of those aspects or aspirations of government at all. I think there are things that can be done to get people to engage more and the professionals have a big role to play here to break down the communication barriers". **Mike, Carer, Interview 4.**

"I do not think that definition of self-care is realistic and I think there should be some reference to partners/carers and other involved in the self care of long term conditions. For my husband he is able to self-manage but he would not be able to self care without my and the families support". **Sarah, Carer, Interview 3.**

The health and social care professionals were also asked about their views of the DH definition of Self Care:

"I think it depends on what stage they are at really. Some of the newly diagnosed chaps just want information and a bit of advice then they are quite happy to go off and do it themselves. Whereas those at the intermediate stage are just people who have a lot more demands on the services that they want, usually wanting to be seen by a physio or OT. Also the education they are given as they go along and the information so that they know where to access and then sort of do self-referrals at the later stages". **Professional 12.**

"I think statements like that are often a bit simplistic and I think there is a balance to be struck between both management and people still wanting guidance and expert help and opinion. I think in the past certainly from a biomedical perspective medicine has been quite paternalistic, and I know people have awful stories from the past, in relation to how they've been given the diagnosis or not given them the diagnosis of MS, and I suppose that people have been treated, treated as children really". **Professional 5.**

These comments demonstrated a wide range of views on these subjects and the importance of RRMS being very individualistic. The discussions continued around the importance of knowledge and information, independence, self pacing, understanding MY MS, lifestyle changes and what was important before and after MS. Some participants felt that self-care could mean that the person with RRMS is an active informed participant in the relationship with professionals, adheres and understands treatment regimes and communicates adverse effects and questions. People talked about the coping mechanisms that they adopted and found worked for them and what kept them motivated to stay positive, be in control through their self-efficacy and to self-care for their RRMS and collaborating with professionals. They talked openly, with compassion and strength of how they learned to live with RRMS incorporating it through the transition into their daily life and learning to make the changes and accept the complex meanings of coping with the ups and downs.

"But as soon as I knew things were moving again I did feel much better and knowing something was going to be done just made me feel really positive again. It was just that I knew things were going to happen and it just made me feel so much better that somebody was taking notice of me and listening to me and that they were going to try another drug. I was really down because I felt that something was not happening quickly enough but my positiveness and determination control it for me, but there have been times over the last few months when I have felt down, very down but you have to pull yourself up from that. You have to find ways to get back up, it can be turbulent but you bounce back again, you really do and it is all down to self-control I really do believe that". **Amy, MS 1, Interview 3.**

"MS has changed my lifestyle in that I cannot do any walking without holding onto somebody and I could not walk down to the park or whatever without suffering for it. That is probably about the worst because it makes me look drunk. Then there is my

eyes as well and everything really because if it was not for all the things that I have I would be working and doing much more. My lifestyle is more restricted with what I am able to do and having to pace myself but I make the most of the opportunities and do as much as I can when I can". **Michelle, MS 2, Interview 5.**

"I think it is best, for me personally to continue with my life as normal as possible, and just to carry on through the transition which is helping me cope with any problems". **Richard, MS 3, Interview 2.**

"The Consultant wants me to try self-catheterisation but I do not want to do that and I am resisting as much as I can. I really do not feel ready to do that yet and I feel that I can cope with controlling what I do and always knowing where the toilets are. I hate when I want to do something but I have not got the energy and I try and fight it. You never think that can happen to you but I pace myself but sometimes I expect too much and I have always been like that". **Mary, MS 4, Interview 3.**

"Yes I have made the transition in accepting my MS as I have had to as I have no other choice. You cannot fight it you have to learn to live with it and I use the word combat and I do think can I subconsciously learn to combat the disease and its affects. I do think that is a bit of trial and error trying things to see if they work and how much I can get away with and working with and through it as part of my life. So with MS that is what I try and do and the more I am able to do helps to further develop my confidence but I am a confident person anyway". **Ian, MS 5, Interview 5.**

"I don't find any part of the MS hard to cope with. None at all. I mean there are physical barriers but nothing is an obstacle when there are ways around most things. I mean sitting here if I see something in the garden that needs moved it would be great to just walk to it, you know. But you know you cannot do that. So you wait till somebody comes in and you say to them that needs moved. I have come to accept my physical limitations but I would not say it was frustrating, you have got to accept that you cannot do it, if you just spend all your life worrying life would just not be worth it, would it. Eighty percent of worry is unfounded, so why worry that is a good philosophy that as life it too short". **David, MS 6, Interview 5.**

These comments have been selected from the transcripts to provide an overview and mixture of the kinds of issues and coping mechanisms that this group of people with RRMS have discussed in going through their transitions of self care, self-efficacy, coping and motivation.

Ability and Willingness to Self-Manage

The meanings of self-management to the people with RRMS, their partners/cares and those involved professionals will be shared in this section of the research findings. Generally they felt that supportive networks and collaborating with other people with MS was also important for people to learn from each other and share their experiences and achievements with self-management. There are however, currently huge gaps between the Government policy drivers to encourage self-management, the actual practical application due to poor coordination and integrated care, lack of resources, training and preparation of professionals and the reality of what happens in terms of encouraging active involvement and responsibilities of people with RRMS. From this group of 6 people with RRMS and

6 partners/carers none of them have been given the opportunity to attend an EPP and none of them had actually heard of the EPPs. Even the professionals were vague about the EPP and did not seem to value the program for this group of people.

“Things like the expert patient programme it has been ran a few times in North Tyneside but I don’t know how many people with MS have attended or get referred to it”. **Professional 11.**

“The thing is with the EPP is that it generates, from the people who attend that meeting they generate the trainers for the next meeting – but you have got to have enthusiastic people and people who are going to go out and find information”. **Professional 9.**

There were also discussions about people with MS missing out because they were not big acute care users and the issues of compliance or agreeing with advice that is given by professionals. Resources also being directed to LTCs like COPD to keep people out of hospital.

“I think the MS patients always get a raw deal because they are not big users of hospital services. You know unlike other people with LTCs, they do not go to hospital very often. They do in crisis but even in crises they are not in that often unless they have to have a really bad relapse to do so. That is why I think perhaps that funding has not been redirected at this group for self-management historically. When you think of things like COPD where people are in and out of hospital then you can see why they want to prevent hospital admissions and keep people at home”. **Professional 11.**

“I am thinking about a client of mine when they won’t take the stair lift and they are managing themselves real big time and they have not taken the advice which has been given. They are making that choice and it is self-management but it is not in their best interest. It is a bit bizarre because sometimes you get them keep coming back with the same problems and you think yes you will have ongoing problems when you do not like the solution”. **Professional 15.**

“I think that if patients can self-manage that their treatment and the way they are looked after will be much better and quicker. They feel in control. I think personally I feel if it was me that this is happening to, this is my body and I have a right to know what is going on, and should be in control”. **Professional 7.**

There was then a dialogue within the focus group regarding breaking down communication and artificial barriers and ways of having more integrated care. Some concerns were raised with regard to creating too much work, having resources to provide better care and looking at the possibilities of a Case Coordinator Role. Currently the Community Matron role was stated to only work with minimal effectiveness with people with complex conditions, but there are plans to increase the number of Community Matron roles in order to meet the Government’s targets. There were also some feelings that parts of self-management were compliance with professional advice, adherence to treatment plans and concordance with medications. People with RRMS feel they should be

able to decide for themselves when they want and need modifications as this is part of the transition and acceptance of their LTC.

"If I do not hear from somebody within about 3 months then I give them a courtesy call, yes and ask the people. It is amazing what you can ask on the phone. Then they suddenly say well actually I have been having a little bit of problem with – so you are able to help make the decision that they do need to ask for something". **Professional 8.**

"That is a problem when they wait to be asked because some people will just chug along until they get to a crisis, whereas if you are proactive and ring them up you will get to see them earlier. I think there are reasons for not ringing people though because we are wary of generating more work sometimes". **Professional 15.**

"That is the aim of the Community Matron role to have somebody who is coordinating, managing and supporting and then sort of directing their care. Also being the named specialist as required". **Professional 8.**

The people with RRMS discussed what self-management means to them in facing their daily challenges which may be with them for the rest of their lives. They discuss the fluctuating abilities to self-manage within the boundaries of their RRMS in terms of relapses and remissions and pacing themselves to be able to undertake their activities of daily living. They describe the self importance of being able to do activities which they valued and were able to cope with by various means.

"Self-management is still happening I have actually just ironed the work shirts this morning. I am carrying on just fine but with the odd relapse I was slowed down but it was not a big issue I just coped by pacing myself and doing things more slowly. I would say that now it is not as easy as it was". **Amy, MS 1, Interview 6.**

"I am still able to do everything for myself and I just take my time in the house and I can do everything eventually but it does take me longer to keep the place tidy. I go to the physio exercise class, the gym, swimming and I use my trampoline just to keep moving and stay fit but also to help me lose weight as well". **Michelle, MS 2, Interview 5.**

"I am still trying to go to the gym and do my Pilates but as things have been so busy over the last few weeks I have not done as much as I should do but I will get back into my routine as it helps my fitness and coordination. To me self-management is my knowing of the things that I need to do and that I have to do these things within the time available to me to do them". **Ian, MS 5, Interview 5.**

"What was important to me before MS was my work and I cannot do that now so that has been a big sort of smack that I have had to give that up. That is the hardest thing that I have done, that I had to do and I had no option. What is important to me now is the same my husband and my family. Also managing to be mobile and I try my best to be and being able to do the things I normally want to do like looking after the house, my husband's meals and the general everyday things like shopping and looking after myself". **Amy, MS 1, Interview 5.**

The partners/carers tried to be very supportive with self-management and continually aimed to empower the person with RRMS and only helping out on specific tasks. They encouraged behaviour changes and new coping strategies to keep them active and able to come to terms with physical limitations particularly post-relapse. They saw this as a way of maintaining the person with RRMS own

involvement in their self management, self-efficacy over their own treatments and motivating them to do more to keep fit and active.

“He is doing everything himself and his own injections and looking after himself totally. The only thing I do and I have done this for a while he sets his tablets up a week at a time in a little thing and I have to do that because he cannot push the sections and they are such small tablets and he has got big hands to start with and he keeps dropping them”. **Helen, Carer, Interview 2.**

“He is empowered and he still does as much as he can even now. He even tries to get himself off of the chair and once the extension gets sorted we are going to get him a chair that will come up and give him a bit more support when he is getting up”. **Sarah, Carer, Interview 5.**

The research participants in this study all supported self-management and self-efficacy and in the main recognised the importance of people with RRMS being involved, as much as they are able, in their own care. This included taking medication and therapies, making lifestyle changes, day to day decision-making about actions to be taken and other preventative measures for their own safety and to minimise risk. There are however some people with RRMS who are prepared to overdo things in order to maintain their own independence, self-efficacy and demonstrate that they are in control. Experiences were shared through all three groups of research participants in terms of what happened when people with RRMS overdid things, their fears of using mobility aids especially wheelchairs and learning the lessons.

“You can make changes to your independence and your control going as long and it can make you more determined. One of the things with the MS is it gradually works, it gradually comes up on you. So I think if you are in the right frame of mind, or in a particular frame of mind then you accept the gradual changes, you know. You have to know your limitations and not go beyond those because if you do you could end up feeling worse for a few days and it is not worth it”. **David, MS 6, Interview 6.**

“I still see myself as myself but I now have a disease which has had affects of course, which has affected me as you know, but I am able to take good care of myself with the things that I can take care of. I am the same person of course I am but MS stops me from doing things for example certain physical activities that I would like to take part in such as martial arts because of the timings and what they are and how they affect my MS symptoms. I am aware of what I am able to do and I try not to abuse it and I do not mind falling down and things but I have to take things quite seriously because of the after effects that I may suffer. That is not part of my normal behaviour prior to MS because now I know I cannot do too much as MS bites back if you overdo things” **Ian, MS 5, Interview 6.**

“It is about knowing what your body can do and what it cannot do and not overdoing it as the MS always bites back. She has to learn the lessons but she never does and always suffers from doing too much”. **Denis, Carer, Interview 5.**

“The first important lesson is do not ever take RRMS for granted because it comes back and bites you because for a long, long time she managed to cope with it for years. Then all of a sudden it was a massive bite. You could not believe the massive amount of destruction that it did in that short period of time”. **Sam, Carer, Interview 5.**

The real fears of the wheelchairs and use of mobility aids were also discussed, particularly by the women with RRMS.

"I just never ever want to end up in a wheelchair and will continue to manage without it. I would never ever want that and I do not want any other mobility aids apart from my walking stick, I just want to stay as I am now". **Michelle, MS 2, Interview 7.**

"It is pretty awful to be in that situation anyway but if I want a holiday then I am just going to have to accept using a wheelchair this time, until we see what happens with this drug. Even just thinking about going to the pub for a drink or a meal, if you do not use the wheelchair you cannot get there, so if you don't use the chair you will have to stay home so that will have to happen". **Amy, MS 1, Interview 4.**

"I resent not being able to go to lots of places you know because I cannot stay on my feet forever and I do NOT like going in a wheelchair, I hate that. I have a brand new wheelchair in the cupboard but I just do not want to go in it and I hate it when I really have to. It is helpful if you are in the chair because you can do more but it is uncomfortable sitting in the chair and everybody glares at you with pity". **Mary, MS 4, Interview 5.**

People with RRMS and their partners/carers have used self-management and self-efficacy through coping mechanisms to incorporate the transition of illness into their lives. They learned through motivation, trial and error, pushing their physical limitations and setting up their own thresholds and boundaries. They all learned fairly quickly that if you bite MS it does bite you back and it has sharper teeth than you. However this did not stop them pushing to the limits and doing things to maintain their self-efficacy through self-control, determination and independence even if they did suffer the consequences of an increase in fatigue or worsening of symptoms for a few days. They did discuss learning the lessons and did focus on these issues for some time to come but when their own self-efficacy, self-determination and self-control took over they were prepared to suffer the consequences for a few days in order to do what they wanted to do when they wanted to do it. The emphasis was more in trying to balance things by pacing themselves through better planning, organisation and setting their own personal priorities to make their lives as full as possible.

According to the American philosopher and MS patient Kay Toombs (1992) perhaps the most profound change in body identity occurs when one is forced to relinquish their upright posture and adopt an alternative mode of locomotion such as a wheelchair. The loss of an upright position can symbolise disability in a most profound way which can affect both independence and autonomy. People with RRMS in this study discussed the way people would address the wheelchair pusher rather than the person in the chair and refer to the person with MS in the third person by asking things like "What would she like to look at?" while they were

out shopping in a department store. This type of question is a good example of what is meant by the social construction and normative nature of an (alleged) impaired decision-making capacity (Dekkers 1999). The use of mobility aids were seen more useful and necessary by the men with RRMS who accepted them more readily due to their bodily dysfunctions and used them to assist and enable them to do more. The women with RRMS were much more self-conscious, proud and aware of the visible symptoms and feeling pity, loss of competence and glares at their self-identity being in a wheelchair in particular but also with the use of other mobility aids. The women were prepared to fight and state that they never wanted to use the wheelchair but as demonstrated with Amy if it was the difference of being able to go on holiday or not she would have to use the wheelchair. This was a short transition of forced change which did revert back once the holiday was over, but did result in acceptance that the chair would be used when there were no other alternatives.

Transitional Phase

A transition is the process of moving from one state or phase to another, and in healthcare it may denote people's responses to change in health status such as enhanced well-being or suffering from an illness, both of which can impact on the quality of daily life. RRMS brings with it forced change which disrupts life through the turbulent passage of reality and has the sufferer questioning their own self and identity as discussed in Chapter six. Transitions occur over time and entail change and adaptation, for example developmental, personal, relational, situational, societal or environmental change, but not all change engages transition (Kralik et al. 2006). In contrast to this Melesis et al. (2000) state that people's lives, environments, and interactions are shaped by the nature, conditions, meanings, and processes of transition experiences. They state that transitions are both a result of and result in changes in lives, health, relationships and environments. The emerging understandings of the experience of transition in RRMS are of paramount importance for health and social care professionals and are pivotal to the promotion of self-management and further development of self-efficacy with LTCs.

MS is an illness where the lives of people suffering from it and their families are irreversibly changed. MS is often viewed as a negative experience where people

require continuous and complex management by professionals. In this research the contribution to knowledge and understanding is of the positive aspects of RRMS and how these people made the most of their lives and reconstructed their lives. They continually stated that they had RRMS, but that it did not have them, and that they had to make the most of their lives.

Engagement with Self-management of RRMS

According to Kralik et al. (2004) self-management makes reference to the activities people undertake to create order and discipline in their lives and to remain in control. Barlow et al. (2002) state that self-management may be one means of bridging the gap between patients' needs and the capacity of health and social care services to meet those needs. In order to do this there is further training required for the professionals to help them to ensure that engagement with self-management abilities of people with RRMS are established and maintained in order for the people with RRMS to make self-management part of the transitions within their coping mechanisms.

In this research being engaged in the story telling process seemed to provide all participants with a sense of self-worth and personal power. It seemed to stimulate reflection and give them the chance to think about their own situations, and working out what really matters to them. Many of them stated that they had not spoken to anybody in such depth before and that they had said things that were in their minds but had never been verbalised before. They welcomed the opportunity to share their RRMS journey as they went through the roller coaster ride and the turbulence of the social reality of RRMS. They were also happy for their partners/carers to be involved as they felt they also needed time to share their own experiences and that generally they only jointly discussed the medical and physical aspects of their illness. The ongoing dialogues with the person with RRMS and their partner/carer separately did open up for both of them opportunities to further discuss together the positive and wide range of aspects of living with RRMS and how they had worked through the three major themes of challenge, transitional and transformation phases together.

In working with these people I have been given the opportunity to share aspects of their journey with them through their own personal situations, memories and day to

day experiences over an eight month period of their lives with RRMS. This thesis contains the researchers interpretation of the experiences they decided to share through this phase of their journey as they started to feel more in control and moved on to make the best of their future.

Each transitional experience as they relate to health and life are unique, complex and multidimensional and it is only reviewing these through research that the diverse types and patterns of transitions will be understood, tested and evaluated through clinical practice (Meleis et al. 2000). The data in this research study has demonstrated that people undergo transitions when they need to adapt to new situations or circumstances in order to incorporate change such as RRMS into their lives as it occurs over a fluctuating time. Reconstruction of a valued self-identity (as discussed in Chapter six) is essential to transition and having partner/carer and family support can make this easier to adapt. Through this RRMS Journey in experiencing the transition of the roller coaster with a turbulent and convoluted passage of reality during which time the people with RRMS, their formal/informal carers can look at their roles and ways of coping and supporting the disruptive illness events. These can be further explored through unpredictability and uncertainty; self-efficacy, coping mechanisms and motivation; and ability and willingness to self-manage through the theoretical developments of their MS Trajectory. Changes are occurring organisationally as is the environment with changes which are social (more knowledge and acceptance of RRMS), political (current drivers for self-management) and economic (resources and healthcare costs internationally) contexts. The process can feel like riding the roller coaster where each relapse seems to causes less upheaval and can be traversed in a quicker and healthier fashion.

According to Schumacher & Meleis (1994) the meanings of change that people have, expectations of events, level of knowledge and skills, availability of new knowledge about a change event, resources available in the environment, capacity to plan for change, and emotional and physical well-being all have an impact on transitions. They state that a successful transition is one where feelings of distress are replaced with a sense of well-being and mastery of new skills to manage the transition and change events and further develop confidence and coping mechanisms.

People with RRMS in transition may feel different, may perceive others as seeing them differently; may be more self-conscious and this may be reflected on how they view the changes particularly with the visible and invisible symptoms (See Table 7.1). Awareness of the visibility of these symptoms by professionals could enhance their understanding of RRMS and the support they give to people and their families. According to Donoghue & Siegel (1992) visibility of a condition and its symptoms can have an impact on the response of others to the individual and so can influence social interactions and relationships. Most of the people with RRMS in this study felt very uncomfortable when people could see they were not “normal.”

Table 7.1: Common MS symptoms classified as ‘visible’ or ‘invisible’ to other people.

Visible symptoms:	Invisible symptoms:
<ul style="list-style-type: none"> ➤ Weakness of limbs ➤ Falling over and tripping ➤ Balance problems due to dizziness ➤ Clumsiness dropping things and coordination ➤ Walking and mobility difficulties with aids ➤ Tremors in extremities ➤ Making bizarre movements /twitching ➤ Slurred speech ➤ Skin irritations – itching and rashes ➤ Eye movement and eye in the corner of socket ➤ Swallowing difficulties 	<ul style="list-style-type: none"> ➤ Fatigue ➤ Dizziness ➤ Bladder/bowel urgency and frequency ➤ Pain ➤ Altered sensations: pins and needles, numbness, burning sensations, heaviness, tingling, sensitivity, etc. ➤ Sexual problems ➤ Emotional disturbance ➤ Memory and concentration ➤ Psychological reactions: e.g. depression, mood swings etc. ➤ Visual problems: blurred/ double vision, blind spots, dimming of colour/contrasts

To meet the predicted challenges associated with this increased healthcare burden, the proactive management of LTCs is a key priority for the DH, the NHS, and Social Care Services. Encouraging self care for people with LTCs forms a foundation of this work, and, in the 'Our Health, Our Care, Our Say' White Paper published in January 2006, the DH committed to self care being an integral part of daily life and is all about individuals taking responsibility for their own health and well-being with support from the people involved in their care. Self care includes the actions people take for themselves every day in order to stay fit and maintain good physical and mental health, meet their social and psychological needs, prevent illness or accidents, and care more effectively for minor ailments and LTCs. The DH report "Self Care a Real Choice: Self Care Support" (2005d) stated that people living with a LTC can benefit enormously from being supported to self care. They can live longer, have less pain, anxiety, depression and fatigue, have a better quality of life, and be more active and independent.

The Government policy makers believe that successfully embedding the principles of self care support into professional practice through the use of skills training, information, tools and devices and support networks should make people with LTCs more interested in their illness, more confident in their abilities and more active in looking after themselves. The central focus of the report is to promote discussion between professionals and people with LTCs about what options there are for self care and what support and information is available. To date within this research study there have been no evidence or discussions of personalised care plans and the support and information to self care has been very limited.

Conclusions

This chapter has focused on a wide range of activities around unpredictability and uncertainty, self-efficacy and self-management. The concentration has been around the transition phases of the MS trajectory when RRMS was being incorporated into the lives of those suffering from the illness and their partners/carers. As stated previously these are not discrete linear phases but part of the roller coaster ride of turbulence into reality. The transitional processes explored the way that people with RRMS and their partners/carers incorporated the illness into their lives, coping with unpredictability and uncertainty, and how they looked at the notion, meaning, engagement and application of self-management and self-efficacy. The changes in their health through listening to their bodies and seeing their visible symptoms affect their physical appearance were shared

through their fears, emotions, independence and self-determination. The life they led with their work and their families was altered and the qualities they took for granted were diminishing slightly as they moved through their own transitions. They appreciated the support and advice that was available to them and engaged with the professionals to help them cope and understand the changes and accessed information to increase their knowledge and understanding of MS. The unpredictability, uncertainty and individuality of the course of RRMS were portrayed as the hardest to accept and yet these people were prepared to make the most of living with it and to have a good life.

The next chapter, Chapter Eight, will move onto the Transformation phase and will initially address empowerment, risk and quality of life; then move onto self-control and self-efficacy; followed by engagement and disengagement, partnership working and advice for newly diagnosed people with MS. We will then move onto the vision for the future. The final chapter, Chapter nine, will discuss these findings, the relationship of them to the literature and the implications for the research study, review the aims of the research, the formation of final conclusions and recommendations for further research.

Chapter Eight: Transformation

RESEARCH FINDINGS

Central Theme – MS Journey Roller Coaster – A turbulent passage of reality Major Themes – Challenge, Transition and Transformation

SUB THEMES	CHAPTER SIX: MAJOR THEME- CHALLENGE
Losing control of self-identity	<ul style="list-style-type: none"> • Feeling unwell en route to diagnosis • Reflecting on the diagnosis day • What is MS? • How will I cope?
Denial or Disavowal of RRMS	<ul style="list-style-type: none"> • Why me? • What have I done to deserve this? • It cannot be right • Reactions and readjustments

SUB THEMES	CHAPTER SEVEN: MAJOR THEME – TRANSITION
Engagement in the process through taking more control	<ul style="list-style-type: none"> • How quickly life changes – the illness transition? • Visible and invisible symptoms • Unpredictability & uncertainty • Feeling in control and using own power
Ability and willingness to self-manage to accommodate RRMS	<ul style="list-style-type: none"> • Learning to live with RRMS • Self-care, coping and motivation • Ability and willingness to self-manage • Staff need to listen to what is being said and respect autonomy

SUB THEMES	CHAPTER EIGHT: MAJOR THEME – TRANSFORMATION
Accepting the intrusion of RRMS and regaining control	<ul style="list-style-type: none"> • Empowerment, encouragement & support • Self-efficacy and determination • MY life changes & transformation & making the most of it
Embracing RRMS and moving on and making the most of life	<ul style="list-style-type: none"> • Reclaiming life 'I have MS but it does not have me' • Working in partnership with my own choices and decisions • Vision for the future – making the most of life

Introduction

The previous two chapters have discussed the challenge and transitional phases of the MS journey roller coaster through listening to the voices of the research participants. This chapter moves to the final phase by addressing the transformation of the journey, which was described as the later stages by the people with RRMS and their partners/carers, when they stated that they started to accept the intrusion of MS. They did this through getting their lives back in control by enhancing their self-efficacy, adjustment, coping and enhanced quality and meaning of life. The research participants in general described this phase as taking on a philosophy of life through personal growth, embracing MS and making the best of their lives. In order to illuminate the nature of the research participants' experiences their quotes will lead the discussions with the theoretical underpinnings appearing after each section and summarised at the end of each chapter.

The engagement process with self-management and self-efficacy impacted and fluctuated on the three groups of research participants throughout the findings. In Chapter six the early awareness and challenge of losing control phases were discussed; Chapter seven moved on to the transitional phase of taking more control and starting to incorporate and accommodate RRMS into their lives. In this chapter they discuss how they put their lives back together again, looking at control of their health within the illness and starting to look more to their visions for the future. The journey continues through contextual shared experiences of quality of life (QOL), empowerment, engagement and disengagement, risk and risk aversion, self-efficacy and working in partnership. There was the belief that they had to accept and cope with MS as it was something they had and that nothing would or could make it go away, but it is not in control as they were in control.

Time was taken in the final discussion sessions to map out their individual journeys of their RRMS trajectories, the routes they had taken and to look at the sequencing and express views of how the journeys could be improved (See Appendix VI). They found this process helped them to develop better perceptions and understanding of the way that things had evolved through their adaptation process and things were starting to fit into place more like a jigsaw puzzle. Listening to their experiences was invaluable to the researcher and it seemed that this type of intervention could fulfil a similar function with professionals in meeting the self-management policy goal through personalised care plans.

The roller coaster metaphor also very much came alive in this phase with the propensity to reflect on the turbulent route to reality and how they confronted the changes that life had thrown at them in learning to ride the roller coaster. They were living with uncertainty and unpredictability on a day to day basis with the upward climbing on a good day and the fast downward slopes on a bad day. The speed of the journey increased with the relapses and remissions when they moved through suspense, fear and the potential unknown. This had impact not just on their own lives but also on the lives of their families and friends. They talked about how they moved on through regaining control, getting to know themselves and their close network again, and feeling more secure in identifying the transformation they had been through in learning to ride the roller coaster.

Within this chapter the discussion is through the context in which the research participants thought the transformation brought changes to their QOL through empowerment, engagement, risk, self-efficacy and working in partnership. Integrated care represents the process of the individual with RRMS being able to engage with professionals in achieving a sense of balance of self-management, mastery through self-efficacy, changing life circumstances and living a personally meaningful active QOL. The diverse perspectives of some participants on QOL follow here:

“My actual quality of life is acceptable but obviously I would prefer if I could still walk and carry out the activities I was doing before MS. But I accept my quality of life at the moment and put this down to my own self-management and determination. It does not stop me going out on my scooter and going out and meeting people and going out for meals or anything like that. I can still go out and enjoy myself and my friends also come here so my quality of life and lifestyle are okay and I make the most of what I can do and enjoy myself”. **David, MS 6, Interview 7.**

“I would like to have more energy to do more things than I can currently do. But I do find by taking care of myself, going to the exercise classes and coping emotionally through self-management and making sure I always look good by having my hair and nails done it helps my quality of lifestyle. I suppose you have to make the best of what you can do. Now I am driving again, but cannot walk too far but I do find other ways of doing things and am happy with my quality of life”. **Amy, MS 1, Interview 6.**

“My lifestyle is more restricted with what I am able to do and having to pace myself but I make the most of the opportunities and do as much as I can when I can. We are a close family and we help each other and my own self-management helps to keep a good quality of life. I do not see myself any differently than I did prior to MS, because inside I am still me and the way I have always been. I can still have a good laugh, enjoy myself and make the most of my life”. **Michelle, MS 2, Interview 8.**

“I am in the main happy with my quality of life and wellbeing, I enjoy living alone in my flat where I can please myself and enjoy my own cooking. I look after myself and enjoy the gym, exercising and Pilates which all support my quality of life and my personal satisfaction. I work with the professionals to maintain my MS and symptoms, do my own injections and look after myself very well” **Ian, MS 5, Interview 7.**

Self-management and self-efficacy are dynamic active processes of learning, practicing and exploring the skills necessary to create a healthy and emotionally satisfying life (Lorig 1993; Kralik et al. 2004). The six people with RRMS and their partners/carers all recognised the importance of their personal wellbeing, self-management, self-efficacy and satisfaction as being of individual importance since MS intruded and disrupted their lives. They all discussed a change in their bodies, self and life as known, including losses, which often challenged their abilities to pursue meaningful or enjoyable activities. They were quick to say you have to think about what you can do now, and not look back to what you used to be able to do, and then use your self-efficacy to plan your goals and targets moving forward. They recognised the effect and importance of their reduced activities due to MS

and the importance of family and friends relationships during the times of constant change. Also the importance of self-efficacy through control, being positive, empowered and having self-determination in making the most out of life and having their goals and targets to maintain their role motivation and mastery.

The social benefits of new friendships and relationships through the MSS social and support networks were identified as a positive aspect of living with RRMS. One couple also discussed the positive aspects of their spiritual beliefs and how their long-term faith became stronger and helped them to cope and really kept them strong and able to take control of RRMS, through self-management of the physical limitations that MS brings. The people in this study had clear recognition that they had RRMS but that it did not have them and that they had self-control through creating meaning and mastery of their MS. The self-empowerment helped them in regaining control of their lives through acceptance and accommodation of their illness, preparedness for their symptoms through knowledge and information and managing the flexibility of their plans through uncertainty and unpredictability.

Empowerment, encouragement and support.

The people with RRMS in this study look at empowerment through their experience of living with MS and saw it as a way of transforming their personal philosophy of life with MS being part of their life but not taking it over. The adjustment process incorporated physical, emotional, social, employment related and learning to optimise life with MS through empowerment to maximise health and QOL. Table 8.1 (adapted from Gibson 1991) sets out the process of empowerment as described by the research participants around the themes of this research. The strength of their views were expressed through the following quotes:

“I do not feel I have lost my life to MS as I think MS is part of my life but it has not taken over my life. I am empowered to do what I want to do and to ask my family and friends for help and support as and when I need it. I have control and am independent and I will do what I can to self-manage, but if I need help I authorise someone to give it to me. I will not allow people to disempower me, if I think they are doing too much then I will say so and therefore I can reclaim my independence and self-management”.

David, MS 6, Interview 6.

“I am empowered as when I had been off work over 2 weeks with a relapse I had a letter from the physiotherapist stating I was on the waiting list and I thought I might have to wait 6-8 weeks for an appointment. I really wanted to get back to work and normal life. So I rang them up and spoke to them on the phone and they gave me an appointment in a couple of days. I was empowered to ring because I was concerned about the way the letter was worded and I got sorted straight away”.

Richard, MS 3, Interview 2.

Some of the people with RRMS demonstrate that their personality type prior to MS was empowered as they have continued to utilise it across their trajectory.

"I really like being in control and feel empowered but I do not know what drives it, I just know that I have to do it and am determined to do things for myself. I cannot think of anything that would disempower me but I hate it when I cannot climb about like a monkey, but I am still in control. I do feel empowered and able to ask questions and probe for information and often I am given time to do this. I really do not want the MS to get any worse. I am trying hard to cope with that". **Mary, MS 4, Interview 7.**

There was identification of threats of empowerment and the importance of feeling in control.

"I do feel empowered in using the knowledge and expertise that I do have and I am part of the discussion. In fact sometimes I can be described as being argumentative, if in some situations that they say something that I am unsure about or disagree with, and then I will speak out. I will ask things and want to know things and make sure those things are alright for me so in that way I do feel empowered. I will not take information or instruction without discussion especially if I disagree with it but I feel empowered to ask and make sure I am happy with things before I leave". **Ian, MS 5, Interview 6.**

Again some people were empowered by their nature and had that type of personality with or without MS and the dialogue between empowerment and power over life courses and in relations to the professionals came through within the quotes:

"She has always been very positive and empowered. She sets herself goals and targets and that seems to help her stay in control using her self-efficacy rather than the MS controlling her. We just accept the good days and learn to cope with the bad days the best we can. It is sometimes hard being a carer and we do need support and help as we are living with the MS as well. We provide the love and support to the MS sufferer". **Sam, Carer, Interview 6.**

"He is disciplined and when he sets his mind to things he always sees them through no matter how long it takes. He demonstrates his power and confidence in talking to professionals and he has such a natural way with him he does it in his jovial way but is very much in control. He is so independent and self-caring and wants to do what he is able to do. We do not want to disempower him in any way but to encourage, support and love him. Once he started accepting things and letting us back in, he was a different person". **Sarah, Carer, Interview 5.**

"I think he is empowered and he is quite capable of asking questions and looking into things he is always on the internet. I am pretty sure he knows much more about MS than I do, if he has questions he is not frightened to ask them and if he is uncertain about anything he will ring his GP or the MS Nurses. He is very confident and would not hold back at all. He is more than capable of looking after himself and he works very much with his MS and keeps on top of it and he does not let it stop him from doing the things that he really wants to do. The family were over protective initially when we eventually knew he had MS because he had suffered from stigma and I felt I had to explain to people why he was staggering and that he was not drunk. He was horrified at me and asked me not to speak for him ever again". **Nancy, Carer, Interview 5.**

There were more mixed responses from the professionals in their range of views on empowerment with the people they cared for with MS and there were variations between the individual disciplines.

“We try to encourage them to be independent and provide the therapy support to help them and to maintain their confidence. The multidisciplinary team aims it to provide the one-stop service to empower the patients through pulling together the advice and support they require to help them build up their self-efficacy through confidence and control of their visits”. **Professional 5.**

“Some people do not want to find out about MS they do not want to be empowered but are very happy to be the old fashioned passive patient and turn up at the talk and be talked to and that seems to work. We try to offer for the ones who want to go to the internet the information they need and the ones who liked to be talked to – to come along and get the talks and presentations about MS. But equally well not everyone is able to be empowered – not everyone takes control of their finances, not everyone takes control of their career and not everyone is going to take control of their MS. Okay so while we are not paternalistic for everyone there are some people who at the risk of reinterpretation, do want to be passive and they want the MS nurses and doctors to make decisions for them”. **Professional 3.**

“So it kind of makes the distinction between having a passive role and having your MS managed for you by the likes of us. Or taking control and managing yourself, which some people do. Whether now is the time you are going to have some physiotherapy should be your choice. People do make choices about their care”. **Professional 16.**

The biomedical role (as discussed in Chapter two) often sees medicine as scientific and sees the role of patients as being passive or paternalistic. Whereas, the biopsychosocial model is more about patient centred care and joint decision-making with patient involvement. However, patients are also empowered to choose to be passive at times of turbulence when they may not want to be actively involved in their care processes.

“You say okay then we have got these options and you can do this or you can do that and they say what they prefer. I feel they comply much better when they feel that they have some empowerment and being able to dictate what treatment they want. I think that if patients can self-manage that their treatment and the way they are looked after will be much better and quicker as they feel in control. I had a lady who had a child, and there was school things going on. She was faecally incontinent, so you can imagine she did not want to go out of the house because this is worse to some extent because you can hide the urinary problems – but with faecal if you are sat next to somebody at school they are going to smell you so, you know, she was not going to go out. Her child was going to be doing a play at school and she wanted her Mummy to go to it and it is very important to be able to go and do these things. We met and discussed what the options were and we actually told her that there was such a thing as an anal plug that she could use which would just pop it into her bottom and it would stop the leakage. We tried it out at home beforehand to make sure that it worked and we got everything sorted and it worked brilliantly for the play. So now really whenever she is going anywhere with her child she knows exactly how to control it and she is like a different person and feels empowered to be able to go outside again”. **Professional 7.**

There were many discussions which highlighted areas of disempowerment, lack of compliance and support from professionals and where the people with RRMS and their partners felt discouraged by the systems which they deemed to be unfair. Empowerment is a complex term and people apply different meanings to it and use it in different ways. Here there were perceptions of

Table 8.1: The process of empowerment

THEMES	COMPONENT	CHARACTERISTICS
Challenge	Through the turbulent passage of reality for People with RRMS	<ul style="list-style-type: none"> • Emotional responses: early awareness of bizarre symptoms and losing control of what was happening with body changes. Validation of the diagnosis and that something was actually wrong as legitimatised by the doctor, which was followed by shock, disbelief, fears for the future, vulnerability and risk. Acceptance of having RRMS and feelings of wanting to know what MS was, the why questions and where to go from here. • Cognitive responses: Seeking the information that they felt they could cope with at the time to find out more about RRMS and modelling themselves on other people who they knew had MS. They relied on the health and social care professionals to point them in the right direction and make the right decisions for them at this time. Engaged with the professionals as recipients in their care rather than active participants and required differing levels of family support. • Behavioural responses: sought out responsibility for their health changes such as scapegoating, self pity and differing levels of non-acceptance through resistance, denial and seeking out what they had done wrong. Taking care of themselves and telling family and friends that they had MS and observing their reactions and acceptance. The personal and family frustrations with the loss of the self and the person they felt they were, the uncertain future were the forces that led them to accept the transition and present the opportunities to move forward with life experiences and what RRMS means to them and their self-identity.
Transition	Adjustment, acceptance and reflection	<ul style="list-style-type: none"> • Learning to ride the roller coaster through the turbulence, instability and further challenges which were facing their lives which led to critical reflection of where they were and helped to initiate the empowerment process. They were starting to take more control, adjust to RRMS and develop more confidence in their own abilities and seek out further knowledge in self-care and self-management. • The self evaluation helped to look at the physical and psychological possibilities over time and what they could do about them in terms of their attitudes and behaviours. • The positive thinking and self-control helped to cope with the turbulence and enabled them to see their own situation more favourably in terms of their personal responsibilities and meeting their goals and targets. • The acceptance helped them to move on and direct their attention to problem-solving, coping with the unpredictability and uncertainty and take control and plan accordingly. • There was recognition of the need to engage and prepare to see professionals by listing questions and events in order to be part of the discussions and empowered to be part of the decision-making process.
Transformation	Mastery of intrusion of RRMS and transforming the philosophy of life of illness within health.	<ul style="list-style-type: none"> • There was recognition that their world had changed and had brought new understanding which brought with it firm independence and the importance of self-management. They were not recipients of care but partners in care and the growing confidence and assertion helped them to master control and be fully engaged. • Their strengths, capabilities, competencies and family cohesiveness increased their own sense of power and helped to transform their philosophy of life. • I have MS, but MS does not have me but it is part of me. • The increased self-respect and self-esteem helped them to demonstrate their mastery of control through balance of living with RRMS within well-being and quality of life.

barriers to getting things done where the constraints had limited application to empowerment.

"I think there are definitely barriers for people who say live in their own property and are subject, you know if they need alterations we don't have facilities for that and those are means tested and the outcome of that might be that people are assessed as having to pay for an adaptation and that can be a barrier to people being empowered and independent because they cannot afford it". **Professional 14.**

"Any support or modifications that you want or need are all means tested and if you own your home you have little chance of getting things without paying out large sums of money which you cannot always afford. We tried for a downstairs toilet to minimise the risk of having to go upstairs several times per day but they would not help us with this. When we were both working we could have afforded this but it is like you are penalised for having MS". **Amy, MS 1, Interview 5.**

"We have been waiting over 2 years to get a downstairs wet room and bedroom because of my physical limitations. I have been told that if this was a council house everything would have been done before the Xmas of 2006 when everything was applied for in October 2006. It would not have cost us anything – nothing at all. It does seem unfair if you think the only difference between a council tenant and a private tenant is rent. My MS is getting worse and my mobility is deteriorating but still we are disempowered by being passed from pillar to post between health, social care and the council". **David, MS 6, Interview 5.**

There were criticisms of the systems by professionals and uncertainty of what and when things are actually available to people with MS.

"There are opportunities for carers or enablers to go into the home and support the people with MS, but sometimes it is not that people want care but they would like to be taken out shopping or to do something different. I suppose our role here is to give information and just alert people to what there is and then make a referral through Social Services". **Professional 5.**

"We still have to do an assessment. It seems such an unfair system because those who have never worked get it all for free and others have to pay for everything. It is not their own personal fault that they have a LTC and cannot work. Yet in Scotland and Wales they get all services and home modifications for free". **Professional 13.**

There appeared to be a number of inconsistencies and delays in the provision of health and social support; also priorities appeared to be given to people who lived in council housing or who were a family on benefits with no income coming into the home or those who has never worked. The system was deemed to be unfair and not meeting the needs of families with a person with MS which was also a cause of many of the delays with people having to try and find funding elsewhere to maintain their empowerment and independence. They demonstrated their self-efficacy and self-management in wanting to show they were in control in many ways including the taking of risks as a coping mechanism. These are some of the selected quotes identifying risks in terms of maintaining control and independence:

"There is a pattern with people with MS who try to maintain their independence even though they put themselves at risk. It can be really bad particularly with falls. This lady with MS had a fractured tibia and still insists she can stand to mobilise, this has huge

implications because of her condition, and her bones are also very thin now". **Professional 18.**

"The risks and consequences of her trying to do too much are always there because she is Miss Independent. She refuses to use the commode downstairs and insists on going upstairs and she is very wobbly. I try to help her feel more independent by placing the furniture, but I put my foot down to her on some things, like walking from room to room with a glass or anything that is risky to her like cutlery or crockery in case she falls. It is common sense attitude to prevent accidents when she has enough to contend with". **Sam, Carer, Interview 5.**

"I am always falling but I do not hurt myself, I think this is due to my rugby and judo I know how to fall and I can control the way that I go down. I think all people with MS and other conditions where they are prone to fall – should be taught how to fall safely and not hurt themselves. This is something that the physiotherapists could possibly be doing to help". **David, MS 6, Interview 4.**

There was contradiction with professionals stating people with MS need to plan for the future, but then in practice there is evidence of them dealing with the here and now.

"There may be problems with their home and then they might choose to move somewhere that is not better really. It is as if people are not taking on-board their condition now and knowing they are going to deteriorate. They might move somewhere with a downstairs toilet but then still have to go upstairs to bed, which does not make sense. I think the decisions are made on a short term basis and they do not want to look to far ahead to envisage themselves in a wheelchair for example, but it can take 6-9 months to get a powered wheelchair so they are putting themselves at risk while they wait for mobility support". **Professional 15.**

"But the professional help from the Physios, OTs and Social Services and stuff like that. They say the patient should be informed of everything that is possibly available for them during the course of an illness but they definitely do not do that. When I was first diagnosed an OT came out and said this, that, and the other. But what they do not say is that in five years time, you know, this may be required. In ten years time this may be required. So consequently when you come to them bridges, further down you illness you have got to ask again for help to reduce the risks that you are taking, that you do not know is available. They do not provide you with either the literature or the information or anything to tell you what the full scope of the services are at all". **David, MS 6, Interview 5.**

"My husband was self-managing well but had problems with the stairs and with the toilet being downstairs so we paid to have a toilet put in upstairs. At which time the professionals said we should have applied for that and we would not have had to pay for it. Things were getting worse and he could not sit on the stair lift and lift his feet so he used to stand on it to get upstairs which was really risky but the only way he could manage. So we applied for a wet-room and downstairs bedroom and even secured some funding but we have waited over 2 years by which time his condition got much worse. If only the health, council and welfare could work better instead of increasing the risks". **Carer, Interview 6.**

Risks were seen as the potential for an unwanted outcome with issues that could affect the MS or encroach on the self-efficacy and self-management of RRMS people. There has been a paradigm shift from behaviour to control with risk management in LTCs, as risks are usually seen as being characterised by behaviour, but in this research they are largely under individual control. The way people perceive and use their autonomy to manage risks is embedded in their

personal experience, risk threshold and getting a balance between risk and safety. Central to risk are the issues of uncertainty and unpredictability of RRMS future activities, limitations and outcomes. Risk can be a challenging concept as how people perceive it is very individual and context specific and it is not something that can always be measured or quantified. From the researcher's personal experience in risk management, there can also be difference between professionals and the general public in the terminology, theory, recognition and perception of risk; which can sometimes make communication about risk management more difficult and harder for people to engage with. The journey will now move onto confidence and control.

Self-efficacy

Self-efficacy influences the judgements that people make about what they try to do. People with a high self-efficacy believe their efforts will be rewarded and tend to engage more in their self-management. In this research study there were fluctuations in the self-efficacy levels due to the uncertainty and unpredictability of RRMS at times when people were worried about their current condition due to relapses or antibodies developed against their treatments and their future with physical and psychological limitations. The qualitative data analysis of these discussions is in Appendix V and demonstrates the pattern changes over the eight month period.

During the low perceived self-efficacy periods the people with RRMS became worried about things and threats to their condition, became despondent and apathetic but it did not last for long until they felt back in self-control. Through their sense of mastery they were able to respond and develop choices to approach what they found threatening and reduce their level of anxiety as a result of their increased self-confidence. The positive frame of mind they had helped them to put the pieces back together through their coping skills, understanding of self, others and principles of living which helped to change their philosophy of life with MS. Self-efficacy and feelings of autonomy are facets of life that have been acknowledged as influential in terms of improving emotional wellbeing amongst people with RRMS (Somerset et al. 2003). All six people with RRMS in this study demonstrated some level of autonomy and differing levels of self-efficacy, at differing steps and stages of their individual trajectory which helped them to cope

emotionally and to maintain their coping mechanisms within their own personal journeys. Here are selected quotes regarding the importance of support to maintain confidence and control:

"I would say that my self-efficacy did change since the early stages when you were coming to see me and then when I was having no treatment at all due to the antibodies. There was a bad period when I was very down and waiting for the treatment but that did improve when I felt I was being listened to and that something was going to happen. It seemed like a lifetime waiting to see the Consultant but I tried to remain positive and in control and keeping everything moving at the time. I was much better once I knew he was going to do something even before the new treatment started. My goals and targets kept me going all the way through and I now have my holiday to look forward to". **Amy, MS 1, Interview 4.**

"I have to think about my family and friends and how they are coping with my illness. They are always very supportive but I will stay positive, self-controlled and independent as long as I can. It can be difficult especially with fatigue and sometimes I have to give in to tiredness. I do like to make the effort to ensure I am presentable and want them to see me as this at all time. It is important for me to pace myself, to always be in control and to do things under my own steam and not to be told what to do or when to do it". **Mary, MS 4, Interview 6.**

"As I look back on my time with RRMS I can see what I have achieved and what I have done to meet my goals and targets and I have achieved them. We have reached the transformation of our MS life and we are making the most of it". **Richard, MS 3, Interview 2.**

"MS does not take over me I am still in control, extremely confident, I have self-efficacy and am very able to self-manage and determined to live each day as it comes, so I still feel good about myself". **David, MS 6, Interview 8.**

The self-control and self-efficacy also extended to helping people who were newly diagnosed with MS and the advice and peer support that they would give to them. There was cultural awareness of being cautious about specific advice as MS is such an individual illness and they perceived the journey of each individual as different. There were feelings of pride in being able to help and enlighten others with a similar diagnosis in terms of planning for and looking positively to the future in terms of adjusting and accepting the diagnosis with self-confidence and maintaining independence.

"There are loads of support groups, information and all kinds of things going on for people with MS. I would talk to them about managing the MS and how to pace themselves and learn to be in control and how important it is to stay positive and independent. But you cannot fight it, you cannot fight it and you are not going to stop it as it has already happened. But if you lie down and let it take over you there is a chance you could be in a wheelchair within weeks". **Michelle, MS 2, Interview 7.**

"I would advise them to get as much information about their own type of MS as possible and to become knowledgeable, self-manage and stay in control. It all comes down to the actual physical ability, you know. The most important thing is to get your mind right on what your physical abilities are and that helps to control your physical abilities and what you are able to do independently. **David, MS 6, Interview 7.**

"I would say do not deny anything but accept that you have it and you will learn to live with it a lot quicker. Get as much information as you can cope with about MS from the

MSS and the internet and learn how to live with it which will keep you in control, able to self-manage and to always be positive". **Ian, MS 5, Interview 7.**

"Everybody is totally different with MS and it affects people in different ways so you cannot always generalise. One area most people get is the tiredness and fatigue and they always want me to talk about that and how I cope with it. Sometimes I worry about how much I tell people in case I make them feel more depressed about what can happen and I would not want them to feel worse". **Mary, MS 4, Interview 7.**

The carers also offered their advice to the people with RRMS and their partners/carers from their own experiences and how they felt about things in order to help them cope and come to grips with things.

"I would put my wife in front of them, and the great thing about my wife and I genuinely mean this, is that I think there are others who can technically go through it, but I think if she just went in front of them with her experiences, the barriers she has jumped and how she has coped with things she can do it in such a quiet and subtle way that people realise it is not such a damning incitement at the end of the day. They would actually get the feel for things and the positives and that is so important". **Mike, Carer, Interview 7.**

"I would tell that the denial was good and it worked well for us in terms of keeping things going for much longer and helped us to move beyond the boundaries of MS. For people to get help and information it would depend where they are as the Internet is a great resource and for the NICE guidelines and information on MS and it is more appropriate that some MS websites. The NICE guidelines are very factual, set out what people have and what to expect so I think they are more realistic than many of the other sources. The MSS is also very good and you can search and get questions answered and there is also a help line which is most useful. There are mountains of information available but I would tell them to go to a reputable source rather than chat rooms and unchecked sites". **Sam, Carer, Interview 7.**

There was engagement of the people with RRMS and their partners/carers in this research with each other and with people diagnosed with MS who require information, advice and support. They also really engaged with the researcher in telling and sharing their stories and going through their journeys including the amount of time and commitment they gave to this project.

The next section deals with their thoughts on engagement and disengagement and working in partnership with each other and the professionals involved. They felt they were more engaged when they had more control, which in turn helped their own self-efficacy, independence and self-management.

Engagement and disengagement.

In order to involve people with LTCs and their families in self-management and improve their self-efficacy, it is paramount that they are engaged in their care and are adjust and accept their condition and work collaboratively to control their

symptoms. They need to feel a sense of being engaged in their care and this was reported by the people in this study as being through professionals understanding their position, requirements, concerns and experiences. They liked to be given choice and be part of the decision-making and not seen as a passive recipient or patronised by the professionals. They felt more equal and able to work in partnership when there was no power struggle or that they did not feel that information was being withheld as the professionals felt that they knew better. All of the six RRMS participants felt that they were experts in their own MS. Their own levels of knowledge and expertise and knowing their own bodies and be able to react to and report changes in their condition helped to improve their level of engagement.

They described their engagement with self-efficacy and self-management as increasing as they went through the phases of their RRMS trajectory as set out in Figure 8.1 which demonstrates a cyclical process which moves backwards and forwards with their level of expertise and acceptance of RRMS causing a philosophical shift to assume self-management. The theoretical themes which emerged from this research and contributed to knowledge are: challenge, transition and transformation which formed part of the process in losing control, acceptance of taking more control and having their life in control through self-efficacy. These were described as being connected, as shown in the figure, with their level of engagement in self-management.

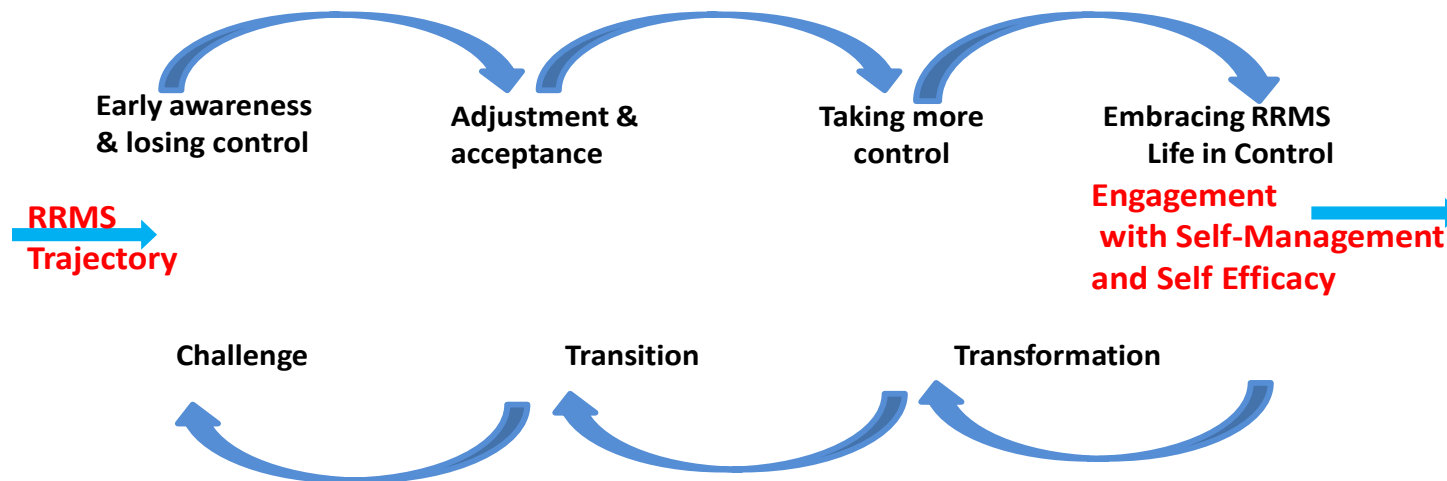
“The doctor came to put the needle in my arm for my infusion and he was about to put it in my right hand. I asked him to put it in the other hand as I needed to use my right hand over the 6 hours when the infusion was running. If I had not engaged with him I would have been really restricted using my left hand. He listened to me even though he had problems getting a vein in my left hand, but I felt that I was in control”. **Amy, MS 1, Interview 5.**

“I like to know what is going on and I like to be part of everything. So I feel really engaged and I like to ask questions and make sure I am in control and have a part to play in the decision-making. It is my body and I look after myself most of the time so it is important I know what is going on at all times”. **Michelle, MS 2, Interview 5.**

“I do engage with the professionals in my support and care and like to feel I am working with them. I do not like it when they withhold their knowledge as I know I am an expert in my MS, but when I ask how other people cope with things they never want to share that information. They see thousands of people with MS but they seem to feel powerful in keeping that information to themselves and not sharing the experiences”. **David, MS 6, Interview 6.**

Figure 8.1 Engagement with self-management & self-efficacy

Philosophical shift – expertise & acceptance of MS with conscious decision to assume self-management



Engaging with self-management can work effectively through working in partnership with formal and informal carers. People with RRMS in this study felt that when their professional's power was used negatively this led to frustration and disengagement. Working with the professionals on an equal level brought improved engagement and a more positive approach to shared care, especially when the people with RRMS felt vulnerable due to changes in their condition, when they felt this relationship treated them with the deserved respect and dignity.

Partnership working and social networking.

Working in partnership with professionals is usually seen as the sharing and reciprocity of information, knowledge and shared decision-making. There can be social networks where the people involved feel part of the process, but care has to be taken to ensure they do not become hierarchies, where they involve people with LTCs who may feel vulnerable at times or if they become too big and then it can be difficult to be truly engaged with too many partners. Social networking with others with MS was stated to have meaning and impact on adjustment, stress and well-being by some people, but had a negative impact on others seeing it as the 'pity-me club'. Communication and keeping each other informed is a crucial part of the partnership working. The most important partners for a person with RRMS is probably their spouse, parents, family and friends, who provide practical physical and psychological support in their daily lives, help them to remain positive, in control and as independent as they can possibly be. This is because most care for this group of people with RRMS was provided at home with the family providing support for self-management and self-efficacy with minimal input from the professionals. There were differing levels of respect and acknowledgement of the professional role as stated below:

"I cannot think of a situation when I do not feel I am working in partnership with professionals. I always feel included and part of the discussions and that I am working with them in my best interest. I am very determined and if I want to do something then I would follow it through. I feel comfortable working with the professionals". **Ian, MS 5, Interview 7.**

"I was down a bit when I went through that bad spell and I did feel unwell but now I am much better and I feel much more positive. It is really good having a happy husband who is never moody or upset or miserable he is always the same every day he is laughing and he is always nice to have as he lifts me up. We are strong partners and do support each other. I also work with particularly the MS Nurses if there is anything I want to know or advice they give me that. I do feel an equal partner with them and we do work well together and I am not intimidated in any way". **Amy, MS 1, Interview 7.**

"I work closely with them and recently I referred myself back to see the physio because I found I had to use a stick for my leg to support my walking after my last big relapse. The OT also came out and assessed me going up and down the stairs with my stick and she felt if things got worse they would put another rail on the stairs. Most of them are willing to work in partnership, there is only an odd person who tries to lord their power over me, but I am articulate enough to cope". **Richard, MS 3, Interview 2.**

"To me the therapy and social care professionals are a waste of time as I have had MS since 1992 I have only seen them about twenty times in total. They spend more time trying to justify their job instead of helping people. The MS consultant has been a pillar of strength and he hid nothing from me and he keeps me well informed and the MS Nurses are also great they are very knowledgeable and keep you well informed and help you through the system. My GP is the best of all of them; he is well informed about MS and is even there when I see the Consultant". **David, MS 6, Interview 6.**

"We need better integration and partnership working with all health and social care professionals being able to work together for the people with MS without the artificial barriers and constraints. Multidisciplinary working is good and better for working in partnership, with patients and their families, if we can bring the services together and fully utilise them". **Professional 5.**

There were a number of mixed experiences portrayed but generally there were feelings that when the professionals worked with and understood how the people with RRMS coped and gave credit for their experiences and expertise in their MS. The professionals had a key role to play but there were sometimes power issues with the professionals expressing control over their knowledge and situations where they may have felt threatened. For example, there were concerns regarding involving the partner/carer in the discussions and key decision-making. Generally people felt this was getting better, but there were a number of partners who described being ignored during the consultation and being expected to take a back seat, for example:

"I have been through the whole journey with my husband and he has wanted me there, but I have always been left sitting on the background and never included in the consultation". **Sarah, Carer, Interview 8.**

However the partners did describe how they were invited along when the diagnosis was being given in order to support the person with RRMS, but the general experience was they were told that it was MS and nothing else followed in terms of what it was or what it meant for them. There were general feelings that the way the diagnosis was shared could be improved with more information, direction and support being given at that time in order to overcome feelings of losing control, helplessness and inadequacy. People felt they were left to fend for themselves and to find out what MS was, what it meant and what the consequences of having it were. Involving partners/carers in MS care by encouraging their attendance at clinic appointments, and consistently assessing

patients' and caregivers' needs, will enhance the provision of services to this population. The next section reviews joint decision-making.

Decision-making

The partners/carers felt they should also be included in the decision-making with the consent of the person with RRMS. Mutual acknowledgement of expertise and the existence of a trusting relationship between all three groups were felt to be necessary for the people with RRMS and their informal carers to be empowered to take part in the decision-making processes. For people with RRMS, their partners/carers and the professionals to feel confident enough to participate in meaningful decision-making they all needed to demonstrate a good working knowledge of RRMS, and its consequences in being able to recognise illness changes, manage symptoms and develop coping mechanisms. This would help during periods of uncertainty and unpredictability where complex decision-making is required to respond, plan, prioritise and solve problems which would help in using intuition about the health care problems. Intuition plays an important part in influencing decision-making for all three groups and can help to minimise risks and allows people to self-manage and to act autonomously with freedom and responsibility. This would allow each group to act intentionally with trust and understanding and free from controlling influences in choice and decision-making.

The concepts of decision-making capacity and competence have close ties to the concepts of autonomy and independence. Professionals and partners/carers need to recognise and respect the person with RRMS rights to autonomous decision-making and the need to protect them in receiving the optimum care. This requires in-depth knowledge of and interaction with the person with RRMS, in the context of each particular encounter because they can express their autonomy through particular courses of action. Decisions need to be discussed in terms of possible options, information available, preferences and choice in order to be negotiated as well as autonomous. Mental capacity to make decisions also needs to be considered if there are cognitive problems or any other form of incapacity in decision-making. The principles of shared decision-making including concordance in medicine-taking and strategies for self-management should be shared across the three groups to ensure there is a common understanding and integrated

working together in partnership. Following the sharing of their perceptions, experiences and concerns the focus was on their vision for the future.

Vision for the future.

Each of the people with RRMS and their partners/carers were asked about what they felt like on a good day and bad day with MS and also their vision for the future. The following quotes are some of their visions for the future. The first three are non-disease focused but family/personally orientated.

“My vision is to stay together as a happy family and to self-manage my MS as long as I possibly can and to stay fit and healthy, coping and remaining as independent as I can be. I value the support of my husband and family as we are all very close” **Mary, MS 4, Interview 8.**

“My vision would be to get my girlfriend here in Newcastle and get things sorted out. To get a job and things all being well will fall out from that, with regard to routine changes and looking after myself these are my ambitions. That is what I want in truth to have a job and sort out my relationship and I would like to be a father one day” **Ian, MS 5, Interview 7.**

“My vision is to continue to cope with MS and take things as they come. I would like to have grandchildren but that is my daughter’s choice and it has nothing to do with me. I believe in living life to the full and doing what we can, when we can and to enjoy it” **Denis, Carer, Interview 7.**

The next three are based around activities of daily living and continuity of independence.

“I would like to have new drugs to control the tremors in my legs as well as continuing to receive and reap the benefits of my infusions. Maybe the new oral drugs which are being researched at the moment might help me to manage better in the future, Anything at all that is going to help my mobility and help me get around, drive my car and maintain my independence. Also the ongoing love and support of my husband and the tower of strength he always is to me”. **Amy, MS 1, Interview 7.**

“My extension being completed with a wet room for me to shower would be absolutely great and to be able to live downstairs without all the problems I currently have in going up and sleeping upstairs”. **David, MS 6, Interview 7.**

“To continue to live happily with my family and have lots of holidays because we love our time away. Maybe for the MS not to get too severe and never to end up in a wheelchair. I would never ever want that and I do not want any other mobility aids just to stay as I am now”. **Michelle, MS 2, Interview 8.**

The last two are more disease focused and looking to the future.

“One of the things that the Consultant said to me was that I would probably end up in a wheelchair but it might not be for twenty or twenty-five years down the line. I know it might happen one day so it is about making the most of things until the time does come”. **Richard, MS 3, Interview 2.**

“Oh my vision is bright and to have lots of nice holidays together. We are going to see soon that our children have made their own minds up and we are going to see more grandchildren. People are getting older like us and we will see more and more conditions and we will cope with things as they are thrown at us and our faith will see us through”. **Mike, Carer, Interview 7.**

Sharing the visions for the future helped in the realisation that they had moved or were moving through the transformation. Refocusing the future helped them to identify new opportunities, life values, hope and aspiration of life with RRMS. Hope is linked to optimism and positiveness and is necessary to demonstrate coping behaviours. Demonstrated through accepting, accommodating, adjusting and coping with integration of the changes, which was part of anticipating the future in that life will go on and it is about making the most of things and enjoying time with their families. It is time to move on as life is for living and we have to make the most of the card that we have been dealt and live it to the full.

Transformation

Researchers, as set out below, have described transformation as an aspect of living with many LTCs and it has been referred to as representing a special form of transition from one way of being to another that is more suited to life with a LTC. Transformation is seen as an ongoing process which is growing as an individual's self-efficacy, knowledge and experience increases in terms of learning to live with LTCs. Within RRMS transformation is seen as a dynamic evolution which is never complete due to the changes it brings through the unpredictability and uncertainty which change the values, beliefs, assumptions and living with MS throughout the trajectory. However, in this research the unpredictability and uncertainty were seen as being used as a basis for self-management and self-efficacy in the restructuring of the lives of the people with RRMS in terms of them wanting to maintain control, embracing their MS and being positive. The stress of the unpredictability and uncertainty drove them to what they described as how they wanted to maintain their competence and capabilities through mastering their control. There was recognition that they could not stop the uncertainty but they could attempt to manage it in order to improve their QOL, well-being and making it part of their daily/family routine.

Theoretical understandings

According to some researchers transformation occurs when the hurdles of illness are replaced by the perception that there is enhancement of the quality and meaning of life, by enabling people to experience life in a way that was previously inaccessible (Lamendola & Newman 1994; Finfgeld 1995; Halldorsdottir & Hamrin 1996). This research concurs with the theory of perception of enhancement of

quality and meaning of life, but as this is a progressive condition, the accessibility is different.

However, Kralik et al. (2004) contend that living with a LTC is a constant process that includes being vigilant of bodily responses, careful planning of daily activities and learning new strategies. There are similarities here as with RRMS there is listening to the body in terms of development of symptoms and trying to stay active through exercise and maintaining mobility through knowing the body's capabilities and having strategies to know what is going on and coping with developments. In contrast Paterson et al. (1999) see transformation as an evolving nonlinear process in which the individual learns to restructure the self and the illness experience through the differentiation of the self. Paterson's research supported the articulation of transformation as the result of a conscious decision to identify and interpret a challenge during which time the individual creates a new relationship with the illness and with those who provide health and social care. Paterson's views of transformation are closest to the findings of this research where coping through self-efficacy and self-management are described as the key goals. Engagement with professionals is seen as important in terms of knowledge, developments and encouragement with self-management and self-efficacy skills including confidence of progression. The contribution to knowledge in this research is that people with RRMS are moving forward through a process of phases of integration through changing their world with new understandings, beliefs and the importance of engaging with self-management and self-efficacy while endeavouring to reach outcomes of maintaining independence, self-control, positiveness, mastery and quality of life.

Taylor (2000) described from her research the process of how women with breast cancer attributed positive meaning to their illness; they described four phases of the transformation process which were: encountering darkness; converting darkness; encountering light; and reflecting light. The positive attitude of people with RRMS and their partners/carers are the strongest experienced by the researcher and the phases identified by Taylor are similar to the analogies of this research along the roller coaster ride. The identification of the roller coaster through a turbulent passage of reality; the turning point of the diagnosis and realisation that they cannot get off the roller coaster; and learning to ride and

accept the roller coaster as their future in embracing RRMS through personal growth, transforming their self-identity and making the best of their life.

Corbin & Strauss (1988) identified the transformation of chronic illness as the restructuring of the illness experience as an outcome of the restructuring of self. They discussed how the aspects of the self change over life courses with regard to the different situations and social relationships in which people find themselves at any given time. Corbin & Strauss (1988) also describe a loss of self when people are unable to complete actions enabling them to carry out tasks associated with various aspects of life such as the activities of daily living. They discussed people with LTCs such as RRMS having the illness coming crashing into their lives where it cannot help but separate the person of the present from the person of the past and affect or even shatter any images of self held for the future and affect their self-identity. As discussed in Chapter six the people in this research through the challenge of accepting the diagnosis went through a restructuring of their own self through a transformation of their self-identity. They described the self-concept of searching for a meaning of illness through the why questions; comparing themselves to others with MS in a positive more favourable way through cognitive optimising; rejecting and denying MS by looking for someone or something to blame; and restoring their self-esteem by developing coping strategies to return to normalisation through finding a place for MS to fit into the context of their lives.

The restructuring of the illness experience was also described by Barton et al. (1994) as a philosophical and cognitive shift in how illness is perceived from a threat and a struggle to that of a challenge to be tackled. This shift was deemed to be accomplished (Moch 1990) by reframing what is realistically possible as well as the losses caused by the disease. Fife (1994) states that in the restructuring of self, the individual attempts to create consonance between self-identity and the identity that is shaped by life events. The philosophical and cognitive shift is similar to the early symptoms and diagnosis faced with RRMS participants who moved through the loss of control and challenge to move forward which was deemed important in making relationships and connections an integral part of successful transitions.

Reflecting on the MS trajectory and illness journey in this research study helped the people with RRMS and their partners/carer to recognise when they started to move on by confronting the changes and adjusting to the illness that caused the turbulence en route and looking towards their visions for the future. They started to recognise that they still had health within their illness and physical limitations which brought them increasing self-respect and improved their self-esteem. In 1986, the WHO, in the Ottawa Charter for Health Promotion, said that health is "a resource for everyday life, not the objective of living. Health is a positive concept emphasizing social and personal resources, as well as physical capacities." Accepting the importance, complexity and multifaceted aspects of health helped them to master their control and independence through better coping mechanisms, self-efficacy, risk management and utilising family support for a better QOL. The lifestyle changes influenced their attitudes towards life with a need to focus on taking care of themselves and being able to self-manage and engage with others to prevent self-dwelling on their RRMS. The relationships between the people with RRMS, their partners/carers and professionals were changing through the self-efficacy of independence, mastery and self-determination. The people with RRMS accepted the changes and that life must go on and they had to make the best of it by focusing on a meaningful life. Professionals need to have a better understanding of these processes in order to support people with RRMS and encourage them by acknowledging their coping through self-efficacy and self-management and making suggestions in the promotion of physical and psychological well-being.

QOL

Self-management and self-efficacy have been identified as important means of increasing perceived control over LTCs and enhancing QOL (Devin & Shnek 2000; Lorig 1993). Motivation of people with MS through the social, emotional and adaptive benefits has led them to believe that they have control over their lives which can help them to reach their desired outcomes. This perceived control is defined as a person's beliefs that he or she has the ability to effect change in various areas of their life to maintain satisfaction in the face of changing conditions and expectations (Bishop 2005). The impact of MS on wellbeing according to Devins et al. (1983) may be mediated through perceived control and satisfaction in life domains as being important to one's QOL.

In this research the importance of control, remaining positive and stressing the importance of lifestyle through wellbeing with exercises and healthy living; obtaining knowledge and information; being engaged and following their treatments by taking an active role in their care processes; and engaging in self-management through maintaining self-efficacy were all important to the people with RRMS and their partners/carers. The contribution to knowledge of these components with these people with RRMS demonstrates the impact on control, engaging in self-care of their symptoms and improved QOL for this research sample can help to overcome barriers of self-management, low self-efficacy and making the most out of their life.

Empowerment, encouragement and support.

There was identification of the importance of education; knowledge and information; communication and partnership working as strategies across the trajectory for maintaining empowerment. In healthcare empowerment has been acknowledged as an alternative to compliance in order to guide the patient-professional relationship. The more traditional compliance orientated approach, where patients are seen as the recipients of professional decision-making is slowly disappearing especially in people with LTCs. Gibson (1991) states that empowerment is a difficult concept to define and is easier understood by its absence of powerlessness, helplessness, alienation, victimisation, subordination, oppression, paternalism, loss of sense of control over one's life and dependency. Empowerment is a process by which people, organisations and communities gain mastery over their own lives (Rappaport 1984). In this research it is recognised that people with RRMS need to be empowered to recognise the importance of their role in self-management, acquire confidence through their self-efficacy and basic skills in order to actively self-manage. Empowered people do their best to prevent their condition from interfering and taking over their life and work in partnership with professionals by being able to make decisions and have choice in opting in and out to what is in their own best interest. Some patients simply want to be given information about their condition whilst others want to have full control over all clinical decisions.

Empowerment was discussed in this chapter within the context in which it was portrayed by the research participants. Most of the people with RRMS interpreted it as a way of moving forward which provided opportunities to learn, be in control and understand RRMS rather than being a victim or feeling stigmatised. There were also displays of symbolising empowerment in changing different situations and sometimes used as a type of bartering process as to when and how to use it. Others had a dialogue between power and empowerment with power over life, management of MS and discussions with professionals. There seemed to be some congruence between the process of being involved in this study and the concept of participatory competence (taking charge and holding on) and interactions with professionals across the MS trajectory which led to increases in knowledge and expertise, trust and decision-making. There was evidence of improved knowledge and learning through social situations with professionals and other people with MS in terms of their critique and different meanings of empowerment.

Enlightenment helped those who were in denial to move on and realise the construction of empowerment was paramount to gaining a better understanding of RRMS and helping to maintain their self-identity. There was recognition that their worlds had changed and brought new understanding and it was time to move on with acceptance and confront the future with the changes it may bring. Seeking out information and knowledge was seen as important in providing opportunities to learn and become an expert in their RRMS rather than be seen as a victim. They were remarkably resourceful in developing attitudes and strategies to incorporate MS into the context of their lives. The importance of their partners/carers was very much emphasised and the family cohesion with emotional and material support both now and in the future. The partners/carers recognised that through good communication, demonstrating love for each other and allowing as much freedom possible; seemed to encourage empowerment in the person with RRMS.

Conclusions.

RRMS is an intricate and demanding illness that affects every aspect of a person's life and mobility including the lives of the people that they live with and their friends. In this chapter there was confrontation of the changes throughout the transformation through having learnt to ride the ever changing roller coaster of RRMS. They demonstrated that they learned to live, rather than simply survive,

and could have a good QOL through self-management, self-efficacy and engaging with all the people involved in their care processes. Partners, family, peers, friends and professionals all provide essential support, advice and assistance related to integrated care and self-management of RRMS. The major support in living with RRMS occurs in the home and social environment with the partner/carer and families being the main caregivers. The turbulent passage of reality that occurred during the acceptance, adjustment, adaptation and integration of life with MS, through the phases of the trajectory, occurred within the family. They were expressed through this research by their words, the stories they told and the metaphors they used to graphically explain how they put their lives back together again.

Their interpretations, meanings and symbolisations highlighted the personal growth within the philosophy of life of the people with RRMS and their partner/carers with identification and transformation of time to move on and make the best out of life. The physical, environmental and lifestyle changes were discussed including the coping strategies and importance of family cohesions and visions for the future. The journey went through empowerment, risk, self-efficacy, engagement and partnership working with clear recognition through prioritising daily life, goals and targets. Their worlds have changed and brought new understanding, strengthened their spiritual beliefs and helped them to embrace RRMS with increased self-respect and self-esteem. They went on to believe that there is health within the illness and it is about putting life back together again now that they have mastered the roller coaster ride by creating meaning and mastery of RRMS with normal life under different circumstances. Through increased information and knowledge they have the key to their independence and control which have been part of the coping process. They then felt that life must go on by stating "I have MS, but MS does not have me or control me, I am back in control". The changes in values, beliefs, ideologies and assumptions have created a dynamic evolution of transformation. These perceptions were corroborated with the research participants, and although their feelings did fluctuate due to their self-efficacy, there was no disconfirmation. This may be distinctive to these six groups of people or may be more to do with RRMS, further research could be undertaken in this area.

Chapter Nine - Discussion and Conclusions

Introduction

This research reveals new knowledge which contributes that people with RRMS go through a process of phases of integration changing their world with new understandings, beliefs and the importance of engaging with self-management and self-efficacy; while endeavouring to reach outcomes of maintaining independence, self-control, positiveness, mastery and quality of life. The last three chapters have outlined the findings of the research and have explored the concepts around the central and major themes. The purpose of this final chapter is to explore the connections between these themes which were generated from the grounded data within this research to the existing literature and theory and to highlight areas where a contribution to knowledge has been made. Also to review the aims set out in the rationale for the research study in Chapter one to determine how these have been achieved. The main overall objective of the research study was to inform theory, policy and practice and provide direction for future research to continually build and contribute to knowledge.

The research study has explored the trajectory journey that people with RRMS and their partners/carers and professionals travel through while in the process of accepting, adapting, integrating and adjusting to RRMS through their positive frame of mind, independence and self-determination. The research has identified the central theme of the roller coaster ride across the turbulent passage of the experienced reality as the process of the research participants' adaptation of living with RRMS. Importantly, the themes that emerged from the research are void of judgements such as good or bad. Although these themes support the idea of the RRMS trajectory being involved in an ongoing process of turbulent movement along a roller coaster path which they have learned to ride, the research has not intended to portray a standard response to the RRMS trajectory. The individual's journey along the turbulent passage is unique to them and cannot necessarily be replicated as the same for everybody. The movements through the main themes of Challenge, Transition and Transformation and back again, on the roller coaster ride are non-linear, sometimes cyclical and potentially recurring throughout the RRMS lifetime changes which force new challenges of uncertainty and unpredictability. The main themes have been separated out for the purposes of

discussion, but the themes and how they inter-relate to provide a complicated, intricate multidimensional jigsaw puzzle of the experiences of people with RRMS, their partners/carers and professionals living through the trajectory.

The wide breadth of experiences from the grounded data, that established the basis for the themes are the building blocks for the Challenge, Transition and Transformation through learning to ride the roller coaster. The convoluted ride with its fluctuations and nonlinear progression is visible in the research findings as a contribution to knowledge as most theoretical trajectories presume a smooth progression. The experiences used in the research ranged from the practical (such as exercising the dog) to the existential (seeking ways of self-management and self-efficacy through developing coping mechanisms and learning to ride the roller coaster).

The undertaking of this research has been an expansive project over three years, which has generated a vast knowledge that is interspersed throughout this thesis. The final chapter summarises the important issues emerging to help the reader take away the contribution to knowledge made and a much deeper and sensitive understanding of living through the RRMS trajectory. Throughout the research there have been a number of theoretical concepts that have emerged from the substantive theory in this research which could be further developed within the contextual nature of the project which are outlined in Figure 9.1. Five main areas have been chosen based on the research aims and their importance to the research participants (these have been highlighted in Figure 9.1) and the MS trajectory. These are inextricably linked and will be explored further through the contribution to knowledge these are: uncertainty and unpredictability; power relations; autonomy and control over the support required; self-efficacy; and through coping strategies. They have all contributed to the explanation of the participants' experiences through the journey of RRMS challenges, transitions and transformation. The contributions to knowledge and understanding from the theory generated within this research will be set out at the end of the chapter alongside the implications for policy and practice.

Aims of the study:

- To explore the MS trajectory through the individual journeys of people living and diagnosed with RRMS in terms of self-management and self-efficacy.
- To develop an understanding of the engagement processes and the different levels of involvement which drive the willingness to be involved in self-management and self-efficacy of people with RRMS.
- To increase understanding of the attributes of self-management and self-efficacy from the construct and experiences of professionals, people with RRMS and their partners/carers.

These aims were achieved through the review of the literature (chapter two) in terms of exploring what was already known with regard to people with RRMS, their formal and informal carers and the professionals involved in their care. The literature review shows that qualitative methodologies are already well-established tools in exploring the lived experiences of people with LTCs. Fewer studies exist that have looked at the particular aspects of the influence of engaging with self-management and self-efficacy across three groups of people: people with RRMS, their partners/carers and health and social care professionals involved in the care of people with MS. The issues discussed are set out through the use of the topic guides around these areas (see Appendix III) with the three groups of research participants, the people with RRMS, their formal and informal carers, during the focus group, interviews and longitudinal studies.

The main purpose of this research was to develop a substantive theory of what it is like to live with RRMS and how does engagement with self-management and self-efficacy influence the people with RRMS and their formal/informal carers. This was undertaken through a rigorous and critical exploration of the experiences of individuals who live with RRMS, their partners/carers and the professionals involved in the care of people with MS.

The research presented in this thesis demonstrates how this main purpose has been achieved by offering a substantive theory of what it is like to live with RRMS and by relating this to the researcher's conceptual framework (Figure 1.1). This theory was developed through rigorous and critical methodological approaches, described in Chapters 3 and 4 which have outlined the philosophical,

methodological and ethical focus of the study as well as describing the research design. The focus has also been on efforts to ensure that this research design possessed methodological veracity and scientific rigour and that the findings can also demonstrate trustworthiness. Most importantly, the perspectives of people with RRMS, their partners/carers and professionals who had lived or were involved throughout the illness experience being explored. They were confident that the emergent theory was an accurate reflection of their own experiences and that the theory did not represent an abstract theory with no clinical relevance or lacking meaning to them.

Theoretical Justifications.

The theoretical framework in Chapter three sets out the qualitative paradigm of this research through interpretivism using a social constructionism, symbolic interactionism and grounded theory methodologies. These are justified in the findings (chapters six, seven and eight) and through the discussions in this chapter in terms of the social construction of reality and eliciting and understanding the way meaning is derived in social situations. Interpretivism was the philosophical stance used to provide interpretation and discovering meanings of the events and phenomena in explaining and understanding the experiences in terms of self-management and self-efficacy. The goal of this interpretive research was in understanding, which changed and developed throughout the research process.

Social Constructionism

The focus of this epistemological methodology was to uncover the ways in which the individuals and groups participated and shared their own reality of their experiences. This was an ongoing, dynamic process in which the reality was reproduced by the research participants acting on their own interpretation and knowledge of self-management and sharing these with the researcher for her own interpretation and analysis. In understanding the consensus of meanings across the longitudinal study these constructions were developed with real perspectives on process (Flick 2009) which provided more insight to the study making this methodology appropriate to this research.

Symbolic Interactionism and Grounded Theory

The focus here was on the dynamic relationships between the different ways individuals give objects, events, actions and experiences with meanings through the processes they go through in order to share these messages. The emphasis being on eliciting and understanding the way meaning is derived in social situations. As the researcher I actively engaged with the research participants and felt they trusted and enjoyed our interactions which enabled me to see things from their perspectives in their own homes. They used symbols, words, metaphors, interpretations and languages including non-verbal communication to share meanings through their behaviours, interactions and social processes. They shared their roles, expectations and feelings from different perspectives including sharing how they felt they were perceived by the partner/carer, family, friends, peers and professionals. This helped in the understanding of how and why things happened in their lives and how circumstances changed over time. This in turn improved understanding of their world through their actions and interactions and the meanings they mediated which assisted in the interpretation of subjective and collective meanings. Constructivist Grounded Theory helped them bring sense and order to these interactions in their social world, within their own natural environment, bringing meanings and actions throughout the MS journey.

These interactions led to shared understanding of the relationships between the people with RRMS, their partners/carers and the professionals. Including the phenomena of self-management and self-efficacy with MS, in particular in relation to the influence it had on the MS journey across the illness trajectory through the grounded theory themes of challenges, transitions and transformation of the roller coaster ride. The researcher explored how the participants interpreted their self-identity and their roles within the context of their interactions with each other and with the wider society. These interpretations are extensively shared in the findings chapters 6-8 which provided evidence of symbolic sharing of information and experiences. The tenets of symbolic interactionism resonated as much with my own journey of understanding as with the journey embarked upon by the people with RRMS and their partners/carers in the study.

Figure 9.1 Possible areas for further exploration

Knowledge and Information	Trajectory Frameworks of RRMS	Risk and Risk Aversion	Empowerment	MS register & mapping database
Local one stop MDT Clinics	RRMS Management Strategies	Integrated Care Management	Adjustment Adaptation Integration	Telling People about MY MS
Uncertainty and Unpredictability	Power Relations	Autonomy & control over support	Self-efficacy Goals and Targets	Coping Strategies
Peer Support	Patient centred approach to home care	Effects of Steroids and DMTs	Partners feelings of helplessness fear & anger	Specialised seamless responsive services
NICE Guidelines On MS	Treatment Plans	Symptom management for better self-care	Personalised Care Plans	Cognitive Issues in coping with self-management

It was always my ambition to explore, with the people with RRMS their own direct experiences and those of their formal and informal carers. They have all shared what it has been like for them to live through RRMS and have described the factors that influenced how they were able to live their lives and cope with this complex long-term progressive neurological condition while at the same time being engaged in self-management, self-efficacy and independence. The work presented in this thesis has gone a long way to achieving the research purpose. However, it is only those who have really experienced RRMS that can really know what it is like to live with it as part of their everyday lives. The work presented in this thesis does get as close as possible to achieving the aims described above, without taking the liberty of suggesting that this theory provides the definitive explanation of all the factors, that influence how they live their lives.

The five main theoretical concepts set out in Figures 9.1 and 9.2 which were chosen to be explored further will now be discussed in turn, although inevitably there will be some overlap between them due to the multifaceted nature of the research and interconnections between all of the theoretical concepts. The remaining concepts could be a focus for future research and developments.

Uncertainty and unpredictability in RRMS

Uncertainty and unpredictability are key components inextricably linked to the RRMS trajectory through the turbulent convoluted movements back and forward through the phases of the journey which are unique to each individual. The effects of uncertainty and unpredictability cannot be controlled but they can be managed through self-determination and empowerment. This is the central theory of the research, with the other themes being congruent with these elements.

Uncertainty is a cognitive state when an event cannot be adequately defined or categorised due to lack of information and is a major factor influencing expectations about MS, treatment and prognosis (Hilton 1992). It is associated with illness, and has complex attributes that typically lack form or structure (Mishel 1988). Uncertainty has its own attributes of probability, perception and temporality which are present in every uncertain situation. In illness, uncertainty is present throughout the events of diagnosis, treatment and prognosis (Mishel 1988). It

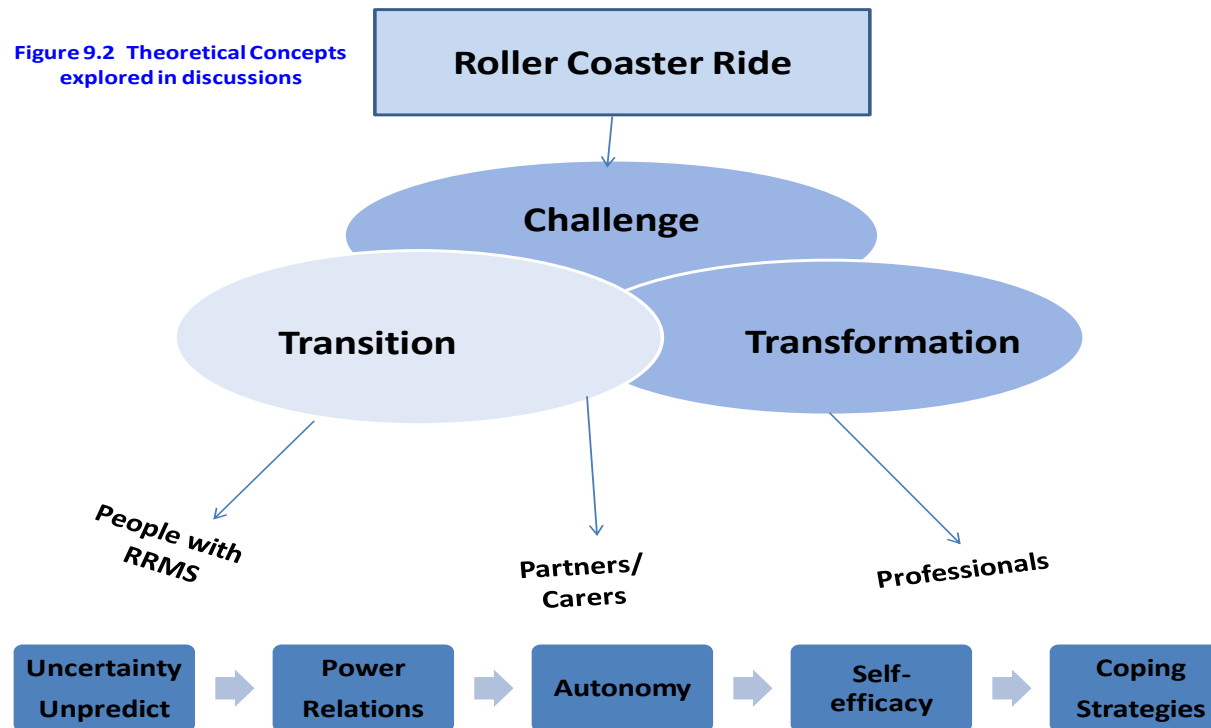
invades all stages of the RRMS trajectory with the recognition of symptoms, learning of the diagnosis and managing the consequences of MS. Situations are complex and include ambiguous, vague, unpredictable, unfamiliar, inconsistent, and unknown factors related to living with an illness (Mishel 1984).

RRMS is variable and unpredictable but usually progressive. The symptoms relapse (due to inflammation blocking the passage of messages) and remit (remyelination) over time, with an overall unpredictability which can be challenging physically, emotionally, psychologically and financially. Lives will constantly have to be changed and adapted to allow for the limitations imposed by the condition. Unpredictability relates to not being able to tell or to forecast the future and can relate to when and how symptoms will reappear or how or at what speed the RRMS will progress. It impinges on not being able to detect the future or not knowing what the future will bring due to the unknown MS trajectory.

Coping with unpredictability was described as being a challenge and often came along with good days and bad days making planning ahead sometimes difficult. With uncertainty there is a known future but the situations of that future are unknown as they are heavily dependent on the progression of the illness. With RRMS, which has an individual trajectory, forecasting (self predictions based on previous experiences), probability/likelihood, perceptions (own interpretation or impressions based on self understanding) and temporality (duration, speed and frequency) are all difficult to speculate.

Uncertainty and unpredictability were inextricably linked with the stages of the RRMS trajectory. They would increase and decrease when the new stages were reached and managed as they moved through the fear of the unknown. The pre-diagnosis stage expressed as being the most difficult in trying to validate the transitions from fluctuating illness to wellness states and hoping that the symptoms would just go away. These symptoms were described as going through cyclical processes of normalisation and de-normalisation until the diagnosis was legitimised. This then presented the challenge of learning to accept, adjust and cope with the illness. The RRMS trajectory was characterised by unpredictability and uncertainty throughout the journey which appeared unique in terms of the

Figure 9.2 Theoretical Concepts explored in discussions



impact it has on the illness, as compared to other LTCs and the prior experiences of the research participants involved in this research study.

MS as a progressive and complex neurological condition is characterised by a multitude of highly variable unpredictable physical, emotional and psychological symptoms that can vary on a day to day basis. It threatens people particularly women at a young age when LTCs are not expected. Especially RRMS where the symptoms and trajectory are characterised by lack of predictability and controllability, with no known cure available to ease the consequences. Its cause is currently unknown and there is no definitive therapy which exists to alter its course as implied through its unique pathway of uncertainty and unpredictability. A person with a diagnosis of RRMS is uncertain about their future health and general functioning. According to O'Hara et al. (2002) MS is a frightening illness that subjects those with the condition to a great deal of uncertainty and places an enormous physical and psychological burden on partners/carers and family members. The progressive impairing symptoms and current lack of cure makes MS extremely stressful and difficult to adjust and adapt to with treatments and therapies concentrating upon alleviating the difficulties it causes. The consequences of uncertainty are conflict, hope and biographical comparisons of the future. MS patients have to cope with the stresses of having a LTC and an incurable illness but also have the additional burden of considerable uncertainty and unpredictability about the future course of their condition.

In this research the first main theme, grounded from the data, was the Challenge presented through early awareness and differing degrees of emotional feelings of losing control. These are personality factors due to fears around what they might have to give up from their current life and the associated emotional components of what affect the RRMS might have on their lives in the future. With most of the people with RRMS in this research these feelings of losing control were short lived as they began to accept, adapt and adjust to the illness and started taking more control as they move through the transitional stage. The two people with RRMS with higher and longer levels of denial/disavowal were going through a more continuous cycle of appraisal and reappraisal which according to Hilton (1992) and Mishel (1990) is part of the uncertainty cycle and the potential psychosocial outcomes that result. Loss of control has a close relationship to uncertainty as it

links a neutral cognitive state with its emotion-filled psychosocial outcomes (McCormick 2002). Mishel et al. (1991) work with mastery, or peoples' beliefs about their ability to act to mitigate the adversiveness of events, defined mastery as an influence on uncertainty through the biopsychosocial adaptation (as discussed in chapter two) as an outcome of coping. Fear was also present at times of relapses with the uncertainty and unpredictability of when, why and how they would happen. Also with any further progression they would cause particularly around independency and mobility with fears of the wheelchair beckoning.

The transformation of uncertainty through hope was turned into an opportunity by going through the challenge and transition of getting life back into control through coping mechanisms and embracing RRMS. This is a contribution to knowledge in this area as most of the current research tends to focus on the relationship between uncertainty and negative psychosocial outcomes. Mishel (1988) hypothesized that people with a strong internal locus of control would be more inclined to appraise uncertainty as an opportunity, but people with an external locus of control would be more likely to appraise uncertainty as a threat or a danger. The control beliefs of people with RRMS were aspects of their perceived behavioural control including positiveness and their perceived capability to perform the behaviours which were influenced by their internal and external locus of control. The partners/carers and professionals recognised how positive people with RRMS are and felt that this helps the transition of positive perceptions of uncertainty which assists people through the transformational process of the MS trajectory by putting meaning and strong coping skills into their lives.

RRMS Positiveness

The positive effects of dispositional optimism on health can be accounted for by self-regulation theory (as discussed in chapter two and see Figure 9.6), which states that individuals with positive expectations for the future are more likely to make an effort to reach their goals than those without such positive expectations. Positiveness appears to promote the use of problem-focused and approach strategies for coping, which are generally more beneficial than emotion-focused and avoidant strategies. A rapidly growing body of empirical research has shown optimism to offer a fruitful perspective for explaining adaptation to a number of health problems including such LTCs as cancer (Friedman et al. 1992), breast

cancer (Carver et al. 2004), Parkinson's disease (Shifren 1996) and rheumatoid arthritis (Brenner et al. 1994).

The people in this research also described the loss of their familiar self as losing direction in life and being unable to see the wood for the trees. The severity of RRMS was being incorporated into their biographical process through contextualisation of their condition. Corbin & Strauss (1988) found similar experiences in their research into a chronic illness trajectory and explained the intrusion of illness separates the individual from the person of the past and shatters images of the person of the future:

‘Who I was in the past and hoped to be in the future are rendered discontinuous with who I am of the present. New conceptions of who and what I am - past, present, and future - must arise out of what remains’. (Corbin and Strauss, 1988: 49).

With the people with RRMS the emphasis moved through their philosophy of life and acceptance of the uncertainty and unpredictability, in comparing themselves to what they could do now. They stated they felt that they were moving forward and not reflecting back to what their life was like prior to MS intruding upon their lives. These people came to terms with uncertainty and unpredictability by developing coping strategies, balancing options, making choices and by keeping informed through improving their knowledge and up-to-date information. The knowledge of RRMS also helped them to gain a better understanding of it which helped them to self-manage as a way of coping through their self-efficacy with their MS. Also getting the right support and being involved in choices and decision-making. Decision theory focuses on human activity where there are options to chose from and is concerned with goal directed behaviour in the presence of options.

In more recent years the focus has been on changing and directing government policies of self-management and self-efficacy, medicine management, therapeutic strategies, education and emotional support. Yet, within this research the unpredictability and uncertainty of RRMS came up in every interview with all three groups of research participants. The unpredictability and uncertainty with the progressive nature and potential for increasing physical and cognitive limitations of RRMS, can make it difficult for people with MS and their families to predict its course and plan their lives. There were feelings expressed about having the right

attitude and a good sense of humour which helped their ability to cope successfully and staying positive was crucial with RRMS being considered as one of those things or has just become part of their life and they have had to engage with it and everything that it brought along the way.

The uncertainty and unpredictability of RRMS confronted people with numerous threats and challenges such as cognitive problems, dealing with pain, fatigue and restricted physical limitations while maintaining a high degree of independence, self-control, competence and mastery. In their efforts to manage these and the other stressors that RRMS brings about, the people with RRMS and their partners/carers rely on social and personal resources, including social support, financial resources, social skills, problem-solving skills and positive beliefs which may facilitate the coping process (Lazarus & Folkman 1984). Lazarus & Folkman's central theoretical position underpins coping as a central mediator in the process of adjusting to RRMS through cognitive appraisal, coping strategies and coping resources through their dynamic model of coping (see Figure 9.3). This highlights the process of stress, appraisal and coping with RRMS over time is possible with adaptational outcomes through psychosocial adjustments to RRMS. Different individuals will have preferred ways of coping in different situations, but the choice of strategy will be influenced by the situation.

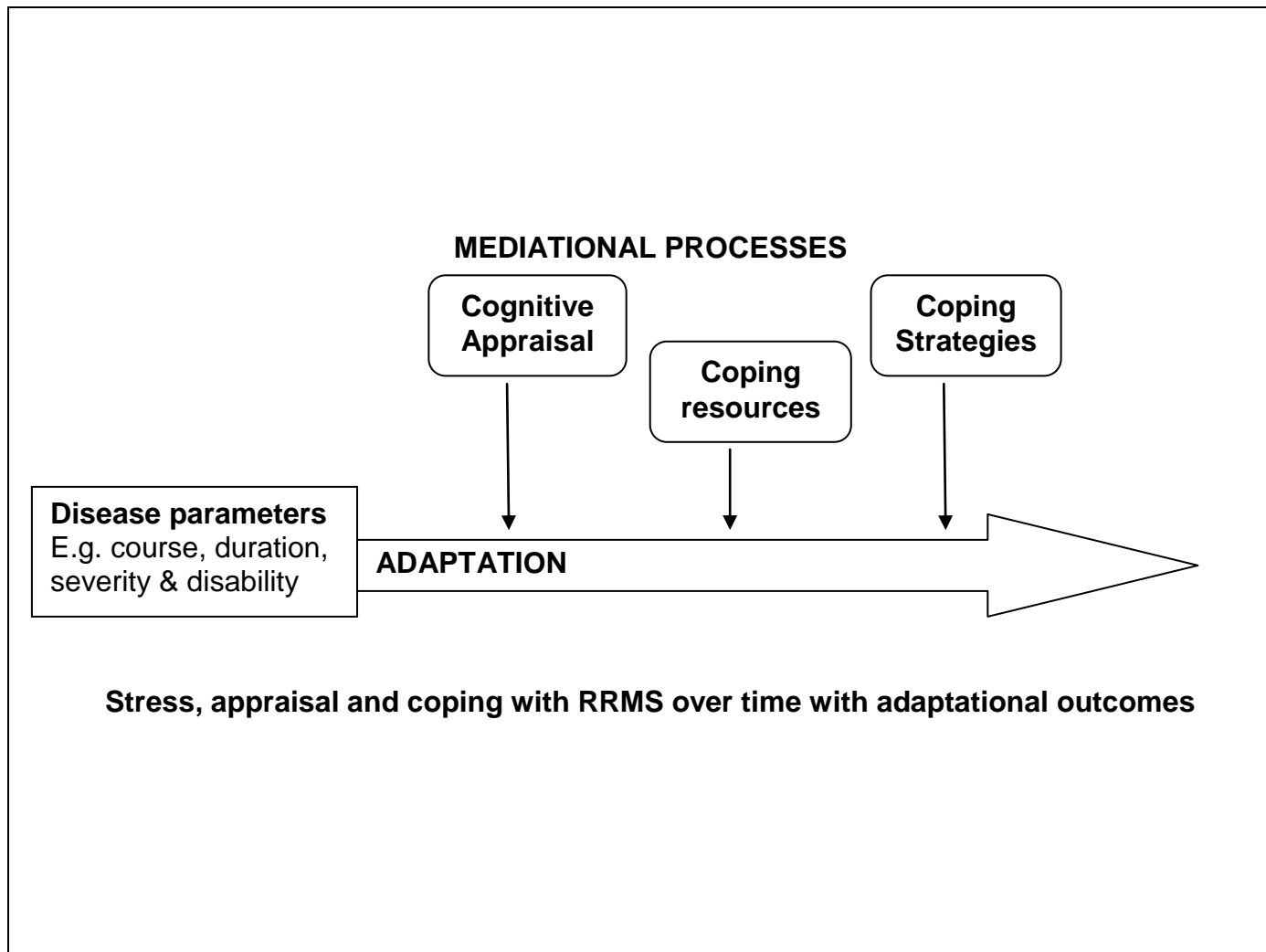
Cognitive appraisal is an evaluative process that reflects an individual's subjective interpretation and understanding of an event. Events are appraised in terms of their threat, challenge and how controllable they are. If an illness related event is appraised as threatening, then it is likely to have a negative influence on the individual's adjustment to MS (Pakenham 1997, 1999). Coping strategies according to Pakenham (1999) are the ways in which people manage demands that are appraised as taxing one's resources. The strategies that have been found to help people cope are in having self-faith, spiritual beliefs, being aware of people who are less fortunate, deciding to fight it, relying on support from professionals, family, friends or peers, or just accepting it. Coping theorists (Lazarus & Folkman 1984; Wineman et al. 1994; Moos & Billings 1982) have generally identified three broad coping strategies which are problem, emotion or avoidance focused.

Problem focused strategies aim to modify or reduce the source of stress directly; emotion focused are aimed at minimising emotional distress; and avoidance confront the source of the stress. Such strategies are used when a situation appears controllable or amenable to change. Coping resources are the relatively stable characteristics of a person's disposition and environment. They are the resources that are available when an individual selects a coping strategy (Moos & Billings 1992). A combination of these types of strategies is used in stressful situations. The style of coping that is adopted by the individual with RRMS would predict the QOL and nature of the coping processes adopted at one point in time would predict the level and range of QOL later (Pakenham 1999).

The people with RRMS face a number of adaptation decision-making dilemmas on a daily basis in the face of uncertainty and unpredictability. Often the uncertainty can be made worse by the professional-patient power balance around their complex needs and intractable medical problems (Power relations will be discussed later in this chapter). Mishel (1988) discusses structure providers which are social support, relationships with professionals and education which directly impact on uncertainty and indirectly through the stimuli frame variable. Loss of trust and confidence of professionals can increase uncertainty and cause stress and anxiety in people with LTCs. Stress and emotional symptoms can be unpredictable and difficult to cope with and were described as easily aggravating a relapse or making symptoms worse at times.

People with RRMS are not big users of acute care services and visits to health and social care professionals are infrequent resulting in more uncertainty and unpredictability. This is supported by Forbes et al. (2003) who state that health and social care provision of people with MS is poor and varies in its accessibility, quality and range of care. Also the MSS survey in 2003 concluded that individuals with MS perceived the provision of support to meet their individual needs within the NHS was poor. Forbes highlighted problems with poor management of the diagnosis (which is consistent with this research); variations in the availability, accessibility and the quality of care and support (again consistent with inequalities, council –v– private housing and those who shout loudest); high levels of preventable complications (lack of action and failure to diagnose complications were prevalent in this research); a lack of information (most people in this research

Figure 9.3 Adaptation of the Stress/Coping Model (Lazarus & Folkman 1984)



were able to self-manage and source the information they required themselves through the Internet and MSS); and poor coordination between services (this certainly caused delays and frustrations in meeting the needs of people with RRMS in terms of lack of integrated support and coordination). Even with specialist MS multidisciplinary teams the infrequency of the visits to professionals for this group of people with RRMS means that they are not able to intimately get to know the individuals and share their MS trajectory.

RRMS Emotional reactions and social conflicts

The emotional reaction of the diagnosis of RRMS can be a greater challenge than coping with the uncertainty and unpredictability of the initial physical manifestations of the trajectory. Lewis (1998) explored the determinants of the emotional reactions to the diagnosis of a LTC. Several factors were found to influence the way an individual reacts to a diagnosis of LTC

1. Personality before the illness in how they coped with and handled crisis before illness with minimal impact and dependence.
2. Unresolved anger or grief from the past which can awaken latent past emotions by the anger and grief triggered by the diagnosis. One of the research participants with MS discussed on several occasions how she was bullied as a child by her mother and at school with the potential triggered consequences of that on her diagnosis,
3. The suddenness, extent and duration of life-style changes mandated by the illness such as fatigue, pain and tiredness requiring rest and self-pacing can be disruptive to life and hobbies. Wheelchair dependence is one of the most serious and recognised consequences of MS and in this study it was something resisted at all costs, particularly for the women with RRMS.
4. Familial and individual resources dealing with stress can influence the experience of the crisis of diagnosis and lack of professional trust. The person with RRMS is watching reactions and cues to the diagnosis and how people perceive their changes in their self and their identity. In order to maintain their self-esteem they also want to hide imperfect parts of their body and use avoidance techniques for people not seeing them during relapses.

5. Stages of individual and family life cycle prior to the actual diagnosis are believed to impact on how they will progress through the different steps and stages of the MS trajectory.
6. Previous experience with illness or crisis as success breeds confidence and if a person has handled illness or crisis poorly in the past they may find the diagnosis of MS too much and lack confidence and control.

Most of these elements were expressed by the people with RRMS and/or their partners/carers during the longitudinal studies and offer insight into the individual experiences of people receiving a diagnosis of a LTC. The findings of Lewis's (1998) study were significant because they highlighted the importance of placing each person within the context and texture of their life and for professionals to assess each individual and deliver a diagnosis with empathy, genuineness, and connectedness. Importantly, Lewis concluded that people who receive a diagnosis of a LTC may find their emotional reaction more disabling than the illness itself until they go through the adjustment process to embrace the person they have become through the illness. All of the people in this research could clearly recall the minute details of their negative experience of receiving a diagnosis of RRMS. The event had made such a profound impact on their and their partner/carer lives. They described the telling as being abrupt in that you have MS but no explanation or discussion as to what it was and feelings that it was lacking in sensitivity, empathy and understanding. They were then left to work it out for themselves due to poor communication, feeling isolated and abandoned by the Consultant, to go through their roller coaster ride of emotions.

One key theme which kept coming through was the desire to have improved communication and sharing of the diagnostic information and ongoing improved support from professionals. Professionals had high levels of knowledge and skills to support people with MS which would help in the management of uncertainty and coping with unpredictability. Once the diagnosis is known a period of adjustment will follow, which in this research was described to be like the bereavement process. Every new symptom can also represent a loss; a loss of personal control over what is happening and possibly a loss of skill. The person with RRMS has to mourn the lost health and adjust to a new identity, to a different picture of themselves. People with LTCs can experience a crumbling away of former self images

without simultaneous development of equally valued new ones which is a fundamental form of suffering from LTCs which Charmaz (1983) refers to as 'a loss of self'.

The challenge undertaken by the people with RRMS in this research was to try and look for new personal meanings within their journey in the search of a new self-identity for the future. Self-identity and transitions are concepts that are closely linked and along with uncertainty and unpredictability are intricate and convoluted processes with forward and backward movements and occur over a time dimension. The professionals involved in this research related to the difficulties encountered by people with RRMS and their families, with uncertainty and unpredictability and inadequate information provision, to help them to understand the impact that these can have on the adjustment and acceptance of the condition.

Adjustment and acceptance of RRMS with the uncertainty and unpredictability was linked to taking more life control through ways of coping with the RRMS such as self-management and self-efficacy. They wanted to maintain their independence and self-control and felt they could do this by pacing themselves and knowing their limitations. They all talked about overdoing things and being realistic or suffering from doing too much over the next few days, hence "if you bite MS it bites you back and has sharper teeth than you" (David, MS 6). Keeping active was seen as important including doing exercises to keep physically fit, managing stress, having the companionship/peer support and for keeping busy through feeling useful. Learning how others coped with the uncertainty and unpredictability also helped to share experiences and learn new tips and advice, but also to learn that others had more or equally challenging things to cope with. The unpredictability and uncontrollability of the fluctuating needs of RRMS influenced by the social world made them feel unsure of the reactions they would invoke from people who were unaware of the invisibility of their MS. They talked about people thinking they were intoxicated as they staggered along and one person was refused admission to a bar where he was meeting a colleague because the bouncers felt he was drunk. It was difficult for them to predict the way their needs and impairments would be met by their family, friends and outsiders.

The use of complementary therapies such as yoga, relaxation, aromatherapy, massages and reflexology also helped along with swimming and Pilates (for balance improvement) as long as there was a balance between exercise and relaxation. A couple of people with RRMS discussed telling their Consultant about the complementary therapies and being encouraged if they thought it would help, although there was some scepticism and feelings of the effects of the therapies lacking in evidence. This suggested a clashing in paradigms in this debate, but feelings of if the MS people thought they worked, did them some good and then they would not do them any harm. They felt that in undertaking these activities and pacing themselves they were self-managing their physical symptoms such as fatigue and mobility and improving their self-efficacy, self-esteem and self-control through their positive attitudes in coping with the uncertainty and being prepared for when the unpredictability did strike. The positive attitude and sharing experiences with others with RRMS helped to maintain their self-efficacy and confidence which contributed to their mastery and self-empowerment and also helped with the coping strategies of uncertainty and unpredictability. This leads to the next section of power relations.

Power relations.

Healthcare professionals are deemed to be experts who are knowledgeable in their areas of training and have the power to cure, care and relieve pain and discomfort. Through this power, by virtue of their knowledge base, they are given trust, authority and control by their patients who receive their services. This should give the professionals a realisation of the power base of patients/carers by recognition of their own power and knowledge base as experts in their own LTCs. In the healthcare professional-patient interaction the balance of power is usually with the experts, as patients expect them to act in their best interest and provide solutions to their symptoms or problems. The professionals work with the patients to maintain their health, ability to work and to take care of their bodies to maximise their fitness, health and contribution to themselves and society. These interactions and communications between the professionals and patients are between people in unequal positions, where the patient consults the professional when they are unwell and require a diagnosis and or treatment through the exchange of information and possibly an examination. Certain aspects of this consultation can influence the patients' behaviour and well-being, for example satisfaction of care,

adherence to treatments, recall and understanding of clinical information, coping with disease and illness, quality of life and state of health and lifestyle.

Medical power

Freidson (1970) stated that medicine was the dominant source of power regarding health and illness as they had control over the content of work, other health occupations, clients and terms and conditions of work. He stated they did this by persuading the public of their efficacy to gain a legal monopoly and to have a sponsorship of a societal elite and the state. Medical dominance was central in the 1970s and 1980s, demonstrated by the growth and extension of medical power, but is much less so today. In the late 1980's the professionals were struggling to maintain their hierarchies of power within health and healthcare. Abbott (1988) stated that professionals, including medicine, were actors struggling to control their work domains and scopes of practice in a field of competing groups. The literature then focused on the professions' actions in preventing or hindering competition while much less was paid to the context within which professional competitions were taking place (Coburn 2006). He stated that the focus on the actors and not their contexts, were explanations of possible changes in medical or other forms of professional power. The continuing influence of writers such as Foucault (1976), with his critique of 'bio-power' on the research agenda of sociologists during the 1990s suggests that changes in orientation may often be 'new wine in old bottle' rather than a truly different agenda.

State control and public economy

State involvement and the public economy face health professionals with more powerful forces when health policy widened and became more visible and health and healthcare was given state legitimacy. Health has become more of a global issue with the costs, equality, control and quality of healthcare being more overtly political. Patients were still mostly seen at this time as passive and deferential in meetings with professionals and were seen as powerless to do anything but obey the advice given from the professionals' viewpoint. But patients were starting to actively evaluate the professionals' behaviour and competence outside of the consultation.

Healthcare confidence

Porter (2002) stated that at the dawn of the 21st century the public had a clear healthiness agenda in staying fit and self-care, as their confidence in the medical profession had been shaken. He states two processes which have resulted in this lack of confidence which are the media influence and the advent of 'high profile' cases. The media is an important source of health information. Health is of prime importance to most people, so it is no surprise that the mass media reflect the interest by devoting a considerable amount of attention to stories about health risks, new treatments, patients' concerns and the politics of healthcare. The cure of MS through the use of stem cells had people with MS mortgaging their homes, spending their savings and borrowing money to pay for the treatment, and whilst developments are still progressing in this area there is no current cure.

The media interest has produced soap operas and factual programmes changing social relations and dominance in health care groups and culture. With the rapid growth of the internet, control over medical knowledge was also being ceded to new types of publically available media and information systems (Bury 2004). The high profile cases of Harold Shipman, Bristol Royal Infirmary and Alder Hey Children's Hospital and other incidents reinforced the view that doctors are neither infallible nor protected from criticism, complaints or the courts. Science and knowledge was also brought into question over bovine spongiform encephalopathy (BSE) and the new variant Creutzfeldt-Jakob disease (CJD) which is likely to have lasting events along with media-led health scares (Bury 2004). The science and knowledge may have also had an impact on the uncertainty of diagnosing some conditions particularly LTCs such as MS where there has been an evolutionary process in response to biomedical and technical advances in the treatment of disease that have created a medically fragile population (Cohen 1999). There is also a growing level of pessimism in this research about the quality of healthcare and the impression that standards were getting worse rather than better.

Patient-professional interactions

Major changes to the context of patient-professional interactions are also taking place with implications for patient-professional relationships and practice. Politicians and policy-makers with government and professionally inspired initiatives are also supporting changes in patient and public involvement in health,

patient centred care and partnership working between patients and professionals all giving greater space to patient involvement and important input. The Government's Modernisation agenda is also promoting patient partnership and shared decision-making in their care with increasing patient power around a shared approach to healthcare delivery. There is also the drive, which has been discussed extensively through this research for people with LTCs, for self-management programmes to enhance quality of life and reduce the demand for healthcare resources (Bury 2004).

There have also been a number of skill mix and workforce development initiatives reconsidering relations between groups of staff, alongside those of patients and professionals in terms of multi-tasking, nurses undertaking medical tasks such as prescribing and surgery. All of these are relate to a shift in the balance between patients and professionals. As Coulter (1999) has stated paternalism may still be widespread in the NHS but patients are growing up and professionals have got to get used to it. However, as Hunter (1994) states the shifting balance may be towards the patient but the medical profession remains firmly in control of key decisions concerning treatment and that patients continue to expect this to be the case. Accountability and legal responsibility for healthcare decisions, especially in life threatening and acute illness, remains firmly with the doctor. There is still much for patients to learn, social changes to occur and for cultures to change to fully implement and see the full benefits.

Patient expectations

Expectations of healthcare are subjective and relative. They arise from personal experiences, from the political, social and cultural context, from knowledge of what is possible and from comparisons with other sectors or other countries. They are shaped by a variety of influences including the attitudes and beliefs of healthcare providers, especially doctors. There can be difficulties with people with LTCs as professionals may not be meeting their expectations of caring and curing. Most people feel unwell and visit the professionals expecting to receive a diagnosis through history taking, examination and a prescription for treatment which is initiated. Within this study it took between 4 months and 6.5 years from the first notation of symptoms to the actual diagnosis of RRMS. During this time there was much ambiguity, uncertainty, frustration, worry, anxiety and depression as well as

fears of cancer or brain tumours through fluctuating symptoms and not being able to lead a normal active life. There were fears that the professionals as well as relatives and friends who thought they were always ill viewed them as hypochondriacs or as malingerers. This proved to be really hurtful as the symptoms were real; there were fears of death and ongoing conflict in relationships.

Self-diagnosis is also an interesting issue in power relations. One person with RRMS through reading, research and discussions with friends and relatives with professional training self-diagnosed MS and discussed this with their doctor who dismissed it. It was seen to violate the doctor's technical expertise in diagnosing MS and was not formally diagnosed for a number of years. Misdiagnosis can produce uncertainty, confusion and frustration and can lead to mistrust in the doctor and even changes in the professional team caring for the patient. Ambiguity of the diagnostic uncertainty can be replaced by a diagnosis which may be welcomed rather than rejected even when it is unfavourable (Bury 1991).

The pattern of fluctuating symptoms and the impact on the social, work and home life continued through the roller coaster ride. The actual diagnosis can bring relief in terms of having a name for the real symptoms, the proof that something was actually wrong and the legitimisation of the sick role. Cohen (1999) describes the 'biographical disruption' encountered by patients when the diagnosis brings to an end one set of uncertainties but at the same time creates another. These require the people with RRMS to confront questions about the nature of their condition going forward and to strategise how they are going to manage and cope in the future. The theoretical perspective for LTCs is negotiated order theory which downplays the notion of organisations as fixed, rather rigid systems which are highly constrained by strict rules, regulations, goals and hierarchical chains of command. Instead there is ongoing interaction between the patient and the doctor with social learning from each other and working on controlling the symptoms and finding an actual diagnosis, what this means for the future and ways of coping and managing the condition.

The correctness of the diagnosis can be difficult and is not straightforward but has become less complex due to the utilisation of MRI scans. Fears of misdiagnosis

can be arduous and the breaking of the bad news by the Consultant can also be an uneasy personal and professional task. During this uncertainty patients can be put into a stressful position of feeling very unwell but not being able to know the actual causation. Poor communication at the time is responsible for as much distress, misunderstanding and ill feeling as at any other period in the relationship between doctor and patient. Equally important are the emotional needs of the person with MS and their family, who are faced with a frightening experience to which they must adjust before they can plan their future. Honesty from the doctor will enhance the patient-professional relationship, and will eventually lead to a greater trust in them by their patient. The special psychological needs of people with RRMS should also be given more priority at the time of diagnosis counselling skills should be made available if required. The illness itself can also cause psychological symptoms which may include memory loss, irritability, mood swings and sometimes dementia. These should be discussed within the patient-professionals interactions and support given when required.

Within ongoing interactions the professionals should encourage and support people with RRMS to ask questions and make their needs known and to complain if they are not satisfied with the services they are getting. When people with RRMS are unwell, having a relapse or reacting to drug therapy, they want help and support to get them back on track, and the sharing of information and action at these times are crucial. A very articulate person with RRMS in this study was prepared to take on a passive role in her consultation just to have a plan of care and new treatment to help her cope with the deteriorating physical limitations due to drug antibodies. Delays and stresses caused by lack of communications, trust and services not being joined-up resulted in a delayed extension for a person with RRMS in this study which can result in physical deterioration due to the extra pressures and risks on the person and the family. Alexander Burnfield (1984) believes that the medical profession has a long way to go in its understanding of the fears and feelings surrounding MS which is still a frightening and mysterious illness. He is a medical doctor and a person with MS.

Autonomy and control over the support required.

Autonomy can be translated into a family of related terms: individual liberty, privacy, free-choice, self-governance, self-regulation and moral independence

(Beauchamp & Childress 1994). They describe personal autonomy as the personal rule of the self, including decision-making and other activities by the individual, that are free from both controlling interferences by others and from personal limitations that prevent meaningful choice, such as adequate understanding. Colony (1995) states that autonomy includes rationality and judgmental coherence which are active expressions of human identity, intention and history based on the self through individuality, character, personal integrity and coherence. He also states that decisional autonomy is the ability to make decisions without external coercion or restraint and autonomy of execution is the ability and freedom to act on decisions and implement personal choice.

For the clinician to respect the patient's autonomy he/she must, at minimum, acknowledge their right to hold views, to make choices, and to take actions based on personal values and beliefs. Information and involvement is at the heart of the patient-centred approach. If clinicians are ignorant of patients' values and preferences, patients may receive treatment which is inappropriate to their needs and therefore does not meet their expectations. When patients are not involved in decision-making and expressing their preferences there is an increase in risk and with the current litigious society people want to see safety as a key issue, and will take action when things are not handled well. From my own research, poor communication, presented in 92% of clinical negligence claims (Wilson 1999) and failure to take account of patients' preferences and choice are at the heart of the vast majority of formal complaints and legal actions. Many clinical errors and serious incidents might be avoided if patients were more actively engaged in their care.

Patient autonomy is the core of the concept of informed consent and is part of the consultation between patients and healthcare professionals. Autonomy goes much beyond the passive process of informed consent, people need information and support to overcome their sense of dependence and achieve as much control as possible and as they desire. According to Raz (1990) the ideal personal autonomy is that people should control their own destiny, fashioning it through successful decisions. The importance of the concept of autonomy in the ethics of the care for chronically ill is to be found more in terms of everyday decision-making than in the more commonly acknowledged decision situations of conflict or of important life

decisions (Dekkers 2001). The *Principles of Biomedical Ethics* state a person is competent to make a decision if he or she has the capacity to understand the relevant information, to make a judgement about the information in light of his or her values, to envisage a certain outcome, and to freely communicate his or her wishes to caregivers or researchers (Beauchamp & Childless 1994).

Much of the more recent work on autonomy and decision-making has been around incapacity within the Mental Capacity Act 2005 which came into force in April 2007 for people with impaired decision-making capacity. Perhaps more consideration should be given to people who are chronically physically ill who need a different approach due to their fluctuating symptoms and cognitive issues where there may be impaired decision-making capacity at times. According to Dekkers (2001) in MS the loss of control of the body occurs in an unpredictable way. Disturbances of motor function and sensation may vary considerably in intensity and over time. Thus, the capacity to make decisions can be dependent on the situation and on the particular decision to be made. The degree of decisional (in)capacity is not totally defined by the presence of particular mental or physical dysfunction, but is related to individual and situational factors.

People with MS can make decisions at most times but there may be times when their cognitive problems may impair their decision-making. It is currently estimated that about 85% of LTCs care is through self-management (DH 2004b). Decision making in people with LTCs can be a difficult process and it may be better to focus on the actual expressions of practical autonomy in everyday decision-making (Dekkers 2001). Independence means autonomy, and autonomy means determining one's own medical treatment (Collopy 1995). These beliefs do lean towards the autonomy and beneficence debate and the concept of autonomy as self-determination. Autonomy states the patient should have the opportunity to decide about their future; while beneficence is an ethical principle that directs the healthcare professionals to seek the greater balance of good over harm for the patients, as those goods and harms are understood from a rigorous clinical perspective. The autonomy of self-determination has been showing itself more recently through the use of assisted suicide to end a life with incurable LTCs. Autonomy through personal choice trumps the choice of family members and the

beneficence of healthcare professionals if the patient can be the necessary and sufficient decision maker.

People with LTCs are often experts in the management and treatment of their own care and are engaged in self-management and self-efficacy thereby reducing their dependence on health and social care professionals. In this research study the people with RRMS and their partners/carers spoke quite openly about the importance of autonomy and shared decision-making across all aspects of clinical, social and everyday life. They recognised the importance of autonomy through personal independence, empowerment, competency, self-determination, self-control and social integration. The partners and families were very encouraging and supportive of the person with RRMS in including them in all aspects of decisions and involving them and their skills in supporting the family. During health and social care consultations the partner/carer was mainly present to support the person with RRMS in ensuring that they remembered all of the issues that they intended to speak to the professional about and were part of any decision-making processes. When there were choices to be made about new treatments or therapies, then the person with RRMS would be given information and discussion would take place, and they would involve the partner if they felt it was appropriate or they needed their input and support. The professionals spoke directly to the person with RRMS and it was the person's own decision as to when and how to involve their partner.

Independence, self-determination and self-control were all very important to the people with RRMS who were involved in this study, which are all highly esteemed values. Autonomy and control are important aspects of self-management and self-efficacy strategies along with social interaction and the impact of partners/carers and families in supporting the regime. Partners/carers and family members can motivate people with RRMS to self-manage, but some can take on too much responsibility and do not encourage independence by wanting to help too much. In this research at times family members would see the people with RRMS maybe struggling to do something and would want to help and sometimes would try and take over. This was not welcomed by the people with RRMS, who had to make it quite clear that they were in control and when they wanted help they would request it, as they did not want to be disempowered or dependent on others until they really

needed to be. Decisional autonomy can exist, as it did in this study with David MS 6 through his self-determination, when his ability to execute his decisions could not be undertaken due to his physical limitations. He was able to intellectually and volitionally direct others to execute his decisions and to do things for him under his direction. Concordance is important with self-management and self-efficacy in maintaining autonomy as it focuses on consultation and shared decision-making rather than on paternalism and being over-protective.

The partners/carers were very supportive and encouraged family and friends not to help unless they were asked to. Sometimes this could cause frustration as it delayed things or was too time consuming but the recognition of the importance had to be emphasised and tolerated. The preference was for activities to be self-initiated, self-directed and self-controlled and in the power of the person with RRMS who had the capacity to engage in the decision-making and self-care. When help was required it would be initiated by the person with RRMS except in emergency situations and this was discussed and clarified within the families. In order to respect autonomy in caring it should only occur in situations where there is mutual responsiveness and human interdependence which are based on the care process being reciprocal. The person with RRMS-partner/carer relationship could be based on autonomy through orientation, identification, coordination and consolidation between them and the family where appropriate (adapted from Moser et al. 2007). In the orientation phase they view their goals, accepting each other's boundaries and creating situations where negotiation could take place. In the identification phase, they would identify the care goals and in the consolidation phase they would find the most appropriate way to interact in meeting these goals through self-management as much as possible. This would mean that the person with RRMS would maintain their independence and self-control over the elements of their care and lifestyle while the partner/carer might provide alternative views which might help to simplify things while at the same time respecting their autonomy. Having boundaries and preferences might complement and enhance the good partnership relationships, which were evident throughout this research, whilst considering autonomy, quality of life and choice of the person with RRMS now and in the future. Autonomy is flexible and changes over time so has to be reviewed on a regular basis and this adapted model may be a way of people with RRMS and their partners/carers assessing this on a regular basis to ensure the

goals and targets are kept up-to-date to maintain self-control and self-efficacy (this will be discussed in the next section).

Self-efficacy

Self-esteem is a concept of personality which describes the extent to which we value ourselves, for it to grow, we need to have self-worth, and this self-worth will be sought from embracing challenges that result in the showing of success. Individuals with RRMS have been shown to have elevated levels of depression, anxiety and other emotional disorders. Changes in what individuals are able to achieve due to limitations imposed by LTCs can alter their self-esteem and self-confidence. Often people can feel a failure or a burden to others if they are no longer able to achieve what they once could which can be demoralising to them. Pakenham (1997) found that adjustment to MS was influenced by other mediating variables such as aspects of the individual's personality, the availability of various types of support and their understanding and appraisal of their experiences. One personal disposition thought to have an impact on adaptation to MS is self-efficacy (Rigby et al. 2003). Self-efficacy is a term that has been used to describe the level of confidence that an individual may have over their own capabilities. This concept is derived from Bandura's Social Cognitive Theory (1989), which states that self-efficacy is an individual's belief that they have the ability to overcome challenges that are presented to them. It is one's own perception of efficacy which proves significant, rather than the actual reality of their ability to overcome the challenge faced. Yet in some circumstances, such as learned helplessness and professional power dominance, people experience events and interactions that 'teach' them to lose their ability to respond effectively to given challenges. Bandura (1994) has argued that people can change their beliefs about 'their capabilities to produce designated levels of performance', and that because much human motivation is cognitively generated this in turn can lead to significant improvement in behaviour (Taylor & Bury 2007).

The theory of self-efficacy as outlined in the literature review (see chapter two) is around the work undertaken by Bandura based on individual capabilities and aspirations. In chronic illness such as RRMS, one's sense of self-efficacy can be enhanced through modelling of self-management skills, guided mastery experiences, and informative feedback (Bandura 1997). Promotion of self-

management could be useful to maximise the person's functional level and quality of life. Self-efficacy beliefs have been related to levels of adjustment to RRMS (Barnwell & Kavanagh 1997) and to be a predictive factor of social activity, ability to control negative thoughts, coping behaviour and incidence of depression (Shnek et al. 1995). Self-efficacy beliefs incorporate concepts such as mastery, self-esteem and a sense of control over the present and future events.

Self-efficacy perceptions play an important mediating role in self-management activities, adopting and maintaining health behaviour changes and health outcomes (Marks et al. 2005; Bodenheimer et al. 2002). Several studies have been conducted to specifically examine whether self-management programmes that incorporate self-efficacy or control-enhancing strategies (e.g., Barlow et al. 1999; Lorig et al. 1985) can produce more favourable outcomes for people with LTCs than standard intervention programmes.

According to Wassem (1992) for individuals with MS, self-efficacy judgements regarding self-care, disease management and psychosocial activity were related to the level of adjustment to the condition. Barnwell & Kavanagh (1997) have also found that self-efficacy has a predictive role regarding social activity and control of negative thoughts in individuals with MS. However, they also found that past life performance to be the most significant overall predictor. Shnek et al. (1995) have suggested that low self-efficacy appears to be related to depression in MS and may also influence coping behaviours. They found that the formulation of coping strategies was impaired in individuals with MS who had low self-esteem.

Coping Strategies

The identification of taking opportunities to exercise control and developing coping strategies have differed in levels and complexity across the six people with RRMS but they have been around areas such as increasing their knowledge and keeping updated with information and developments; concordance with clinical treatments and therapies including medications and advice; reducing stress in their lives as far as possible; taking an active self-control role in their care and maintaining independence (finding fresh purpose and meaning to life); keeping an active informed role within their family and social network (as discussed in Chapter eight people with MS enjoy being involved with others with MS and offering empathy and

advice to newly diagnosed people and those more vulnerable than them); and maintaining exercises to improve their levels of fitness and keeping mobile (these help in keeping their self-identity, self-esteem and social contacts). The theory of planned behaviour can be applied to the understanding of RRMS and the diverse self-management behaviours such as maintaining their self-esteem, improving their knowledge and understanding, engaging in exercises and maintaining their independence and other lifestyle behaviours.

According to the Theory of Planned Behaviour (Ajzen 2007), human action is influenced by three major variables of behavioural beliefs, normative beliefs and control beliefs which are shown in Figure 9.4. The application and relevance of this model to engaging with self-management and self-efficacy through planned behaviours has been set out in Table 9.1 under the variables of the theory planned behaviour model.

Self-management and self-efficacy normative beliefs.

Normative beliefs are the perceived behavioural expectations which in the case of RRMS come from the partners/carers, professionals, friends, peers with MS and other life influences such as spiritual beliefs. The normative beliefs come with motivation and support and concordance with expected behaviour and are subject to individual perceptions and controls. GPs have been rated an important source of information and support to people with RRMS and have the power to reinforce changes in attitudes and behaviours (Coulter 2002). Medical Consultants and MS Nurses can influence behaviour of people with RRMS in their attitudes and beliefs in concordance with treatments and adaptation which are important with self-management and maintaining autonomy and focus on consultation and shared decision-making rather than on paternalism or being over-protective. The research revealed that people with RRMS want to embrace others with MS who are newly diagnosed or their MS has progressed further than theirs as this motivation and support helps them to cope better with their own condition. Other variables such as their new role importance and feeling useful within their social network, their level of disability and physical/social environment can put pressure on their performance of behaviours.

Self-management and self-efficacy control beliefs.

Control beliefs deal with the perceived presence of factors that can facilitate or impede behaviour. Self-efficacy in this research is the belief of the person with RRMS that they have the ability to overcome the challenges presented to them throughout their illness. It is their own perception of their behaviour efficacy which helps them to overcome the challenges faced and their perceived locus of control guides them to perform the behaviour. Locus of control is the perceptions and beliefs related to what they do or do not do. In internal locus of control people see themselves as affecting outcomes of events and believe that their efforts will be rewarded and tend to engage more which may be affected by the predicted resistance to influence from others. External locus of control behaviours can be subject to actions for other people and subject to chance or fate which can magnify threats and worries about things that are not likely to happen. People with a strong internal locus of control would be more inclined to perform the behaviour and look to it as an opportunity for them, but people with an external locus of control would be more likely to appraise uncertainty of the behaviour as a threat or a danger. The control beliefs of people with RRMS were aspects of their perceived behavioural control including positiveness and their perceived capability to perform the behaviours which were influenced by both their internal and external locus of control.

Other research which supports the findings from this research came mainly from the adaptation, adjustment and coping strategies studies. Stuifbergen (2000) found that respondents with MS who were actively engaged in health promoting behaviours were more likely to report a better QOL. Consistent with these findings, Schwartz (1999) found that people with MS who engaged in a training program to improve their coping skills showed a greater improvement in their QOL than did respondents who received peer telephone support. Folkman & Lazarus (1988) discussed the nature of adaptive coping strategies with emotionally-focused coping (e.g., avoidance, self-blame, wishful thinking) is likely to result in lower QOL than problem-focused coping (e.g., focusing on the positive, seeking social support and being problem focused). However, Aronson (1997) found that people with MS who demonstrated acceptance of the condition were more likely to demonstrate a higher satisfaction with their QOL. People in this study expressed satisfaction with their QOL even in times of relapse because they expected recovery.

Figure 9.4: Theory of Planned Behaviour Model (Ajzen et al. 2007)

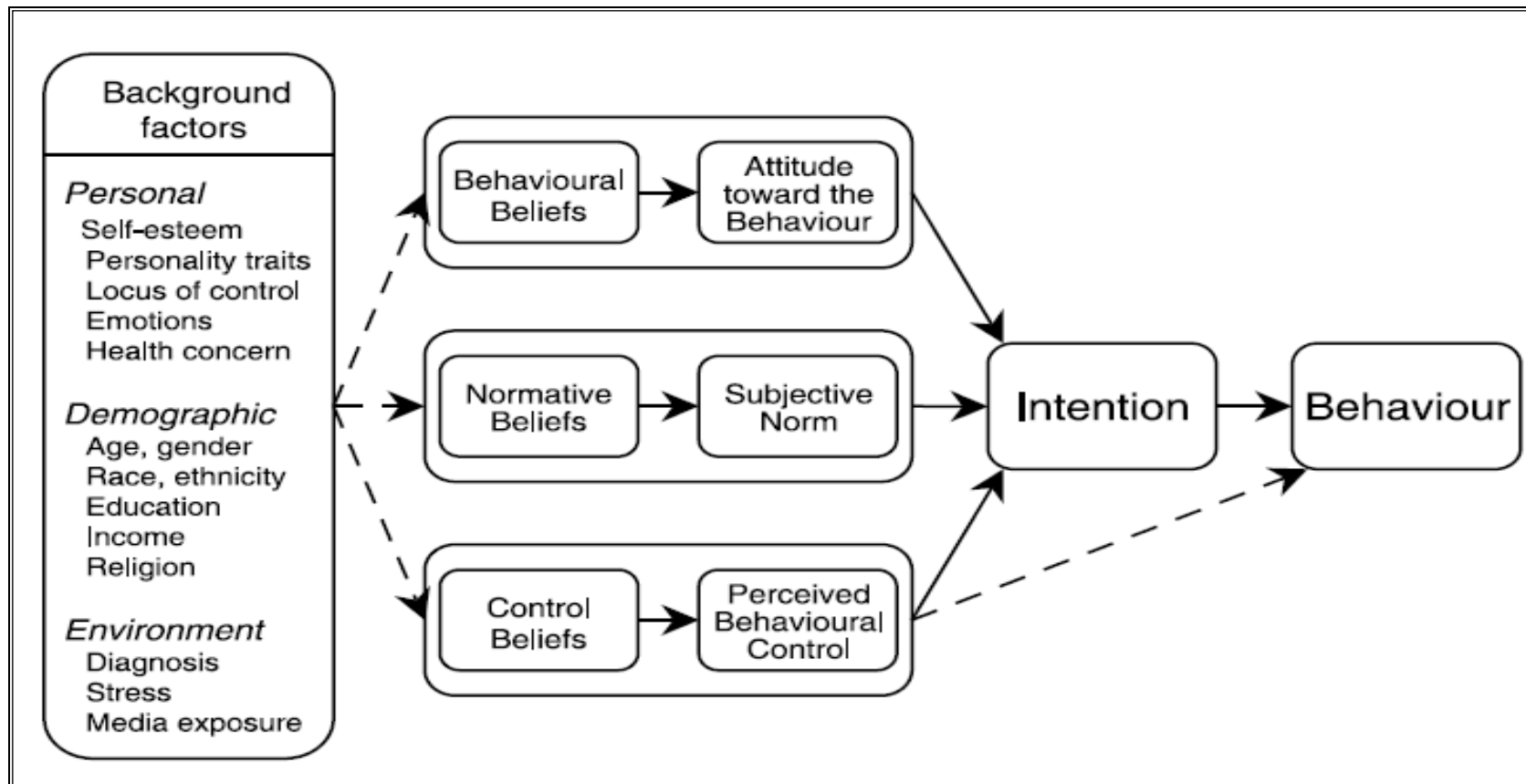


Table 9.1: Theory of Planned behaviour of self-management and self-efficacy

VARIABLES OF THE THEORY OF PLANNED BEHAVIOUR	DESCRIPTION	PERCEPTION OF SELF-MANAGEMENT AND SELF-EFFICACY
Attitude towards the behaviour (Behavioural Beliefs)	Favourable or unfavourable evaluation of the behaviour	Understanding of RRMS, and personal experience of independence, self-control, quality of life and self-identity. Re-establishing a role and purpose in life. (Cognitive Domain)
Subjective Norm (Normative Beliefs)	Perceived social pressure to perform or not perform the behaviour	Psychosocial expectations of adaptation of functional, psychological and social changes. (Affective Domain)
Perceived behavioural control (Control Beliefs)	Perceived capability to perform the behaviour	Demonstrating self-efficacy through self-confidence Locus of control (Internal & External)

Summary of Theoretical Concepts

The preceding sections have considered the theoretical implications of the current research study. The appropriateness of interpretivism, social constructionism, symbolic interactionism and grounded theory as theoretical perspectives have illuminated the way in which people with RRMS, their partners/carers and professionals interpret and perceive the dynamic relationships between meanings and actions and the processes that people go through in order to share their experiences, has been confirmed. There is a link within the RRMS trajectory to the theories of autonomy and independence which appeared to be driving self-management and self-efficacy. A critique of the theory in relation to the current literature has demonstrated gaps in the current knowledge base, in areas which this research has contributed new knowledge, these will be outlined in the contribution to knowledge and understanding section.

Contribution to knowledge and understanding

There are two main objectives in undertaking a PhD. The first objective is to make a contribution to knowledge and understanding in a field of study. The second objective is to enable the doctoral candidate to develop the knowledge and skills required to undertake high quality research. The research presented in this thesis has made a significant contribution to the existing body of knowledge through the presentation of a rigorously developed substantive theory of the influence of engagement with self-management of people with RRMS, their partners/carers and the professionals. This new theory has further developed existing knowledge and understanding of the reality of engagement with self-management and self-efficacy throughout the trajectory of RRMS as the research participants' share their journeys through their meanings, perceptions and actions as demonstrated throughout this thesis.

The experience of the self-management and self-efficacy across the trajectory of individuals being diagnosed and living with RRMS; the perceptions and experiences of their partners/carers and health and social care professionals have never been explored in such a rigorous and systematic way before. It is only by developing a better understanding of the challenges, transitions and transformations that people with RRMS experience that health care practitioners and carers are able to provide comprehensive and holistic care that is meaningful

to the individual receiving care and their family. Through utilisation of the journey route map, developed by the researcher, the theory has been developed across the steps and stages of the MS trajectory (see Appendix VI for personal journey maps) and shared throughout the thesis. This has been undertaken by demonstrating veracity and scientific rigour within the research presented making a contribution to knowledge and understanding in a number of ways.

First the theory has been complex, developed across three groups of research participants, (the people with RRMS, their partners/carers and the professionals) across a longitudinal study with over 14 months of data collection, ongoing analysis and theory development. The result is that the research has new knowledge to offer all people involved in living with, caring for and supporting RRMS.

Second the research has made a contribution to the development of positive transformation and how these people reconstructed and made the most of their lives with RRMS, getting their life back into control through coping mechanisms and embracing MS. Much of the research to date has focused on the negative aspects of uncertainty and obstacles in moving forward.

Third the research has used an established self-efficacy questionnaire qualitatively over a longitudinal study to review the fluctuating perceptions of independence and activity; worries and concerns; personal control; and social confidence. Most questionnaires have been used quantitatively with usually only two measures. The questionnaire used in this research has been related to the roller coaster constant ups and downs throughout an eight month period demonstrating the changes that occurred (see Appendix V).

Fourth a trajectory framework was developed for people with RRMS in this specific area to assist in their understanding and management of their RRMS. Much of the research on trajectory frameworks discuss a linear process as people move through stages and phases as they progress through their illness. In this research it was non-linear, convoluted and colloquially referred to as a roller coaster ride. The people with RRMS and their partners/carers were fascinated by their own journey maps and found the process of constructing them really useful to them.

Fifth the transformation of uncertainty through hope was turned into an opportunity by going through the challenge and transition of getting life back into control through coping mechanisms and embracing RRMS. The more people seemed to be engaged in self-management behaviours with increased self-efficacy they reported having higher levels of quality of life. Much of the current research tends to focus on the relationship between uncertainty and negative psychosocial outcomes.

Sixth the importance of self-control, remaining positive and stressing the importance of lifestyle through wellbeing with exercises and healthy living; obtaining knowledge and information; being engaged and following their treatments by taking an active role in their care processes; and engaging in self-management were all important to the people with RRMS and their partners/carers in this study. The contribution to knowledge of these components with these people with RRMS demonstrates the impact on self-control/self-efficacy, engaging in self-care of their symptoms and improved quality of life for this research sample can help to overcome barriers of self-management and making the most out of their life. There were family conflicts at times, due to anxieties, stress and pressures of coping, but through family support and cohesion things 'normalised'.

Integrated care represents the process of the individual with RRMS being able to engage in achieving a sense of balance of self-management and self-efficacy, changing life circumstances and living a personally meaningful active quality of life. This theory has added new knowledge and understanding to an existing body of knowledge. This includes the multiple research programmes that have examined LTCs or chronic illness experiences in many different conditions. Although it would be difficult to compare between different long-term conditions, there may be some similarities worth consideration in future research and practice.

Implications for practice

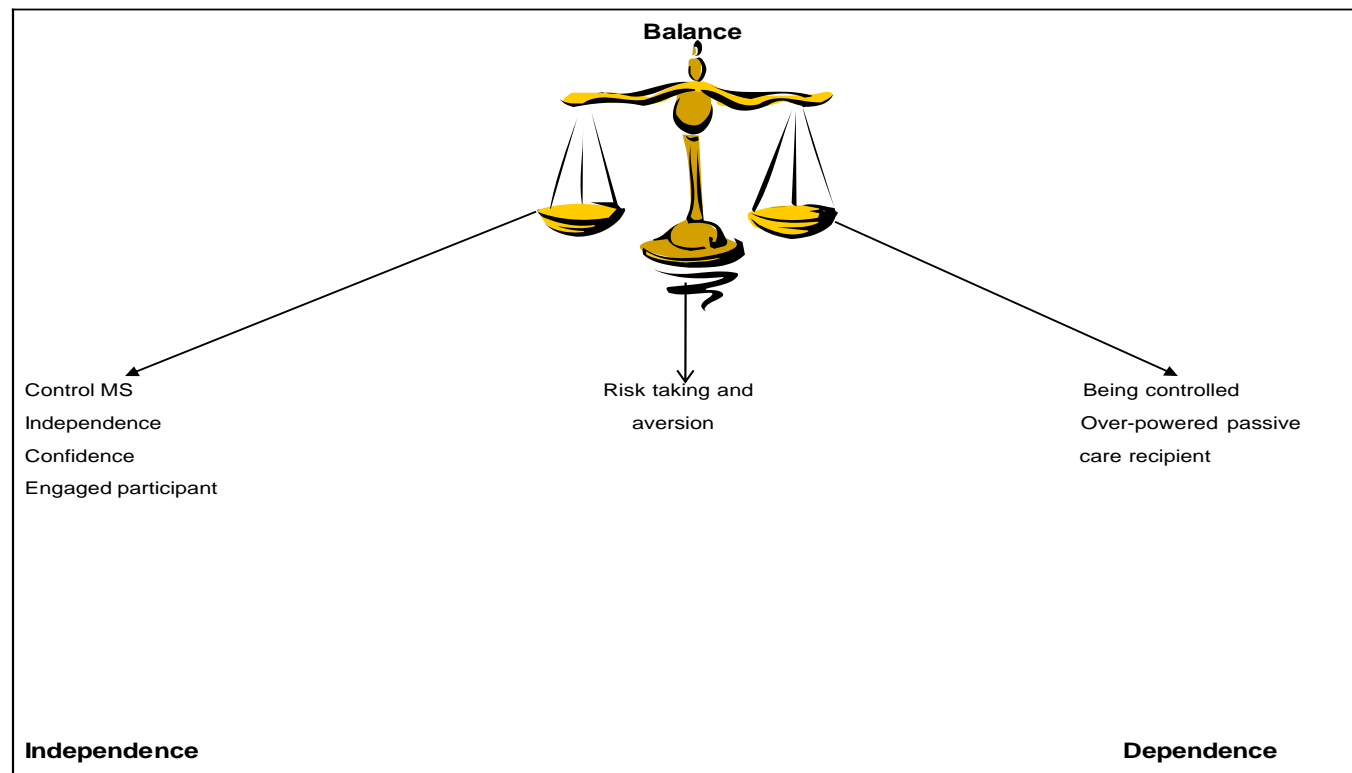
The research has provided rich descriptions and interpretations of the participants' accounts of engaging with self-management and self-efficacy across the RRMS journey which may be recognisable to other families and professionals involved across the RRMS trajectory. These may help to increase the mutual understanding of life changes through the intrusion of RRMS into the family life and

the steps and stages that people go through in terms of acceptance, adaptation, adjustment and integration. The research has opened the door to the importance of engagement with self-management and self-efficacy and the influence it has for people with RRMS and their partners/carers. It has also highlighted the important roles of health and social care professionals in recognising the important information and support these people require to make informed choices, decisions and being an active partner in their own care with the support of their families. The following are all areas that should be considered by the PCT (see also a summary of these demonstrated in Figure 9.6) and the professionals for an integrated journey for all concerned. This is quite a comprehensive list based on the findings from this research study.

- Improving the understanding of how people with RRMS portray their illness, manage it and develop their own self-management strategies and become experts with their families in dealing with day to day activities.
- Empowerment, advice and support are required for people with RRMS to live independently and successfully apply their own coping strategies, perseverance and strength to adjustment and acceptance of their LTCs.
- Professionals require a better understanding of the uniqueness of uncertainty and unpredictability of RRMS in terms of personalisation of the individual requirements and utilisation of self-management plans for people with RRMS.
- Professional advice for people with RRMS and their families should be given in a fair and justified manner, treating them with respect, listening to them and their expertise.
- Professionals should listen to people with RRMS and their families and learn how they cope with troubling symptoms and physical limitations. This would help them to understand and support them in a more helpful and meaningful way.

- Rehabilitation support by the multidisciplinary team should be undertaken by allowing the person with MS and their partner/carer to express themselves to give more meaning to their needs, to see how they feel and what is required to support them.
- There needs to be a balance set between independence and dependence in what is achievable and works for different people in the care process (see Figure 9.5). The balance would set individualised criteria and determine how people want to be involved in their care in safety without taking unnecessary risks. The current situation where there is no or limited discussion is leaving people with uncertainty. The proposed personalised plan could help here.
- During professional visits and consultations there should be a focus on asking questions about health behaviours, goals and targets and any barriers that people with RRMS have in their own self-management and self-efficacy.
- Understanding the challenges, transitions and transformations that people with RRMS, as outlined in this research, go through could help professionals provide a more holistic approach to the provision of care.
- Annual visit/assessments of people with MS should be instigated by a case manager or coordinator. Many of these could be undertaken over the telephone, due to resource implications, as many people do not hear or have contact with professionals for long periods of time. More active care support would promote better QOL and well-being.
- Consideration could be given to the role and purpose of medical support for people with RRMS, particularly those not on DMTs. They are currently travelling miles, partners/carers are taking time away from work and the high associated costs of people going to clinics for a 3-6 minute consultation is deemed not to be beneficial to people with RRMS. One-stop clinics with integrated care and resources are a better method or locality clinics with multidisciplinary input. GPs could become more companions to people with RRMS in supporting them and acting as a gatekeeper to services as and when required. Professionals could act as agents throughout the care

Figure 9.5: Balance between Dependence and Independence



process in directing people with RRMS based on their individual needs and requirements.

- Utilisation of the easy to use self-efficacy questionnaire used in this research, completed immediately prior to the consultation, could provide specific information on how the person with MS perceives their levels of confidence, independence, activities, cognitive feelings and control at each visit. This could be part of the discussions and would help practitioners to understand the ups and downs of the roller coaster and the effects they can have on their levels engagement in the care processes.

Implications for Policy

This research has identified a number of areas where there are differences between policy, practice and reality. These could be due to lack of resources, skills training or general awareness and Department of Health policies have not being fully implemented.

- There was no evidence during this research of any personalised care plans or any patient held documentation to guide emergency treatments or personalised goals and targets. There is a requirement for multidisciplinary team working through integrated care processes documenting and meeting individual patient needs and outcomes
- Being engaged in the story telling process seems to be giving people with RRMS and their partners/carers a sense of self-worth, personal power and therapeutic value. It appears to stimulate reflection and gives them the chance to think about their situations and work out what really matters to them. Use of a personal care plan would be useful with professionals listening and allowing them to express what they are feeling. These experiences and ways of coping would also be useful to other people with LTCs.
- There has been very limited support or information available for people with RRMS to encourage self-efficacy or promote self-management. There was also a lack of integrated care and collaboration between service providers.

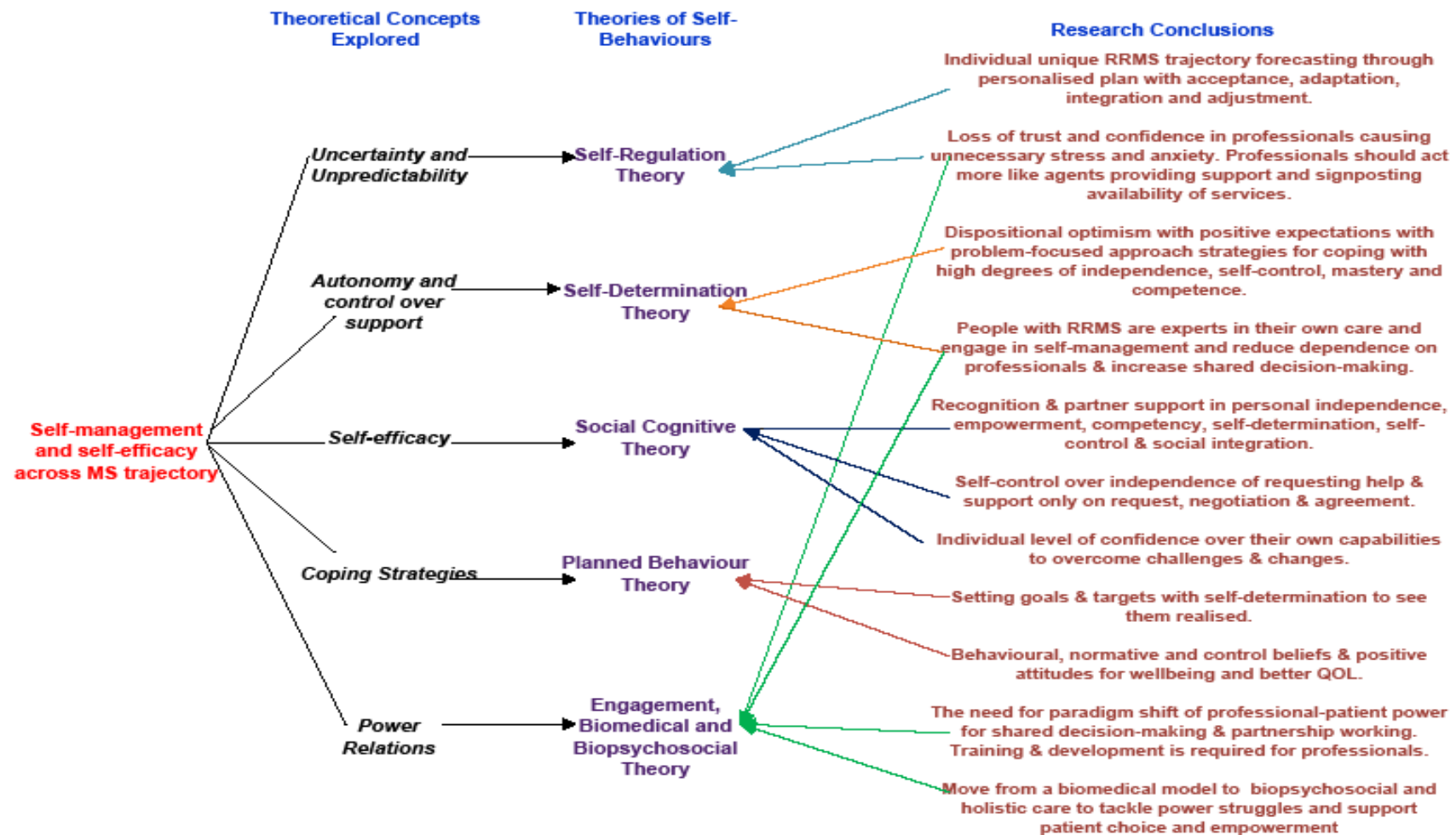
- The EPP has not been utilised or heard of by any of the people with RRMS or their informal carers. The professionals themselves did not value the EPP therefore did not refer or advise people to attend.
- To understand the theories of self-management behaviours (see Figure 9.6) and their impact on self-management and self-efficacy in terms of the findings in this research could enable discussions around ways of implementing the findings accordingly.
- Skills and knowledge training for staff in areas of empowerment, partnership working or shared decision-making appeared to be non-existent. The role of community matron/case manager did not exist for this group of people.

Implications for research - Strengths and weaknesses of the research

The research study was designed to get in-depth information, interpretation and perspectives from the research participants. This involved over 100 interviews and a focus group over a fourteen month period of data collection time which was quite extensive. The research design and topic guides were user-led with input at the development stages. Most of the people with RRMS and their partners/carers seemed to really value the opportunity to share their experiences which became stronger with life changing adjustments and increasingly meaningful to them over the longitudinal study. Often the interviews did continue for 2-3 hours minimum which were recorded and transcribed. Cross data analysis was undertaken at each session to confirm the previous findings and with the central and major themes. All transcriptions were undertaken by the researcher including the coding and theory generation which resulted in thousands of hours undertaking the research. This may have been a weakness due to the time constraints over the three years of the PhD. However, in retrospect I am not sure I would have undertaken it differently as the value to the researcher and the research participants has been clearly recognised. The next research study will be undertaken with a team of researchers in order to have the support and sharing of ideas.

All of the people with RRMS and their partners/carers were always positive, even through their unpredictability and uncertainty. There was no disconfirmation of this positiveness. It is possible that this could be due to the sample recruited or it could

Figure 9.6: Theoretical Basis of Research Conclusions



be a common feature of people with RRMS and their partners/carers, but the findings were grounded in the data collected.

As discussed throughout the thesis, a key strength of the study has been the attention to quality and rigour as has been demonstrated by the use of reflexivity and relationality, in particular in relation to the co-construction of knowledge and meaning with the participants. In addition, the issues of credibility, trustworthiness, dependability, confirmability and transferability have been addressed throughout.

Recommendations for further research

There are several areas where MS could be further explored through research to improve services, control strategies, wellbeing and quality of life. These are a few ideas which could be developed further.

- The role of positiveness in the adjustment and acceptance of LTCs within the current models of healthcare.
- The ways in which doctors decide when and how to break the diagnosis of MS.
- The understanding of health and social care professionals of the concepts of uncertainty and unpredictability of LTCs and how these should be individualised within personalised care plans.
- The utilisation of Integrated Care Management and multidisciplinary pathways of care could support individualised care and ways of sharing joint care processes.
- Further exploration of the self-efficacy questionnaire to see the impact it could have when utilised as part of professional consultations. The questionnaire could be a useful tool for clinical and research assessments of psychosocial adjustments in people with RRMS.
- The impact that informal carers contribute to home care of people with MS.

- Utilisation of personalised plans for people with RRMS which can be shared by people with MS across the health and social care professionals and emergency admissions and treatment staff in the acute care sectors.
- Bridging the gaps between Councils, Health and Social Care to provide a smoother transition for modifying homes of people with RRMS in a timely way to support independence and self-control.
- Identification of ways of improving quality of life through integrated support and maintaining independence for people with LTCs and their families.

Final Conclusions

As discussed in the introduction, my motivation for carrying out this study was my professional and personal experiences of patients and friends who have lived with long term conditions and the assumptions that were made around how they could cope with all aspects of their lives with little or no support. Yet the Government policy makers are stressing the importance of involving patients with LTCs in self-management and self-efficacy to reduce the burdens on the current health care systems.

I sought to contribute to the knowledge base and understanding of the concepts of self-management and self-efficacy in terms of reality, meaning and interpretation of those involved in the progressive neurological LTC of RRMS. The research has demonstrated that living with RRMS is an ongoing process and that meaning and experiences can change as the illness and daily life circumstances change. The uncertainty and unpredictability of RRMS confront people with numerous threats and challenges yet the findings of this research revealed that the transformation of uncertainty through hope was turned into an opportunity by going through the challenge and transition of getting life back into control through coping mechanisms and embracing RRMS. Hope is linked to optimism and positiveness and is necessary to demonstrate coping behaviours.

By engaging with self-management and self-efficacy behaviours people with MS and their informal carers felt that they had enhanced their perception of self-control, QOL and well-being. The relationship between self-care, self-efficacy, self-

determination, subjective QOL and personal well-being were discussed in relationship to the positive outlook of people with RRMS and the importance of engaging with self-management throughout this research across all three groups of participants. Self-management which seems to increase a person with RRMS perceived control and subjective QOL should be supported by partners/carers and professionals.

Health and social care professionals should be made aware of the important influence of engaging in self-management and self-efficacy, which have become evident from this research, and how they could provide support to people with RRMS. They should also be aware of potential personal barriers to self-management and self-efficacy, such as the lack of information and internet access; stigma; social isolation; physical, cognitive and emotional barriers; financial limitations; and use of physical aids to improve activities of daily living and mobility; and address ways to overcome these. Giving people with RRMS time during consultations to discuss how they are coping, and focusing on asking questions about health behaviour and goals and targets at each visit would help to identify any barriers they have in self-management.

The theoretical basis for many of the research conclusions has been set out in Figure 9.6 and these include a number of areas in the building up of self-management behaviours and breaking down barriers through increased recognition of self-efficacy and the coping mechanisms which are developed by people with RRMS and their formal carers. There is a wealth of information which could be shared with other people with LTCs in their well-being and QOL and in support of policy implementation. Professional training and development is required in a number of these areas to develop their skills and knowledge and in the transference of this to their patients and families. Through this, professionals could act more like agents, who provide signposting and support to the services and facilities which are available as well as medications for symptom control. Most GPs do not have the same depth of MS knowledge by their generalist nature which is required for the full scope and remit of patients that they see. Perhaps GPs could become more of a companion, as well as the gatekeeper for referral services, and provide the friendly emotional adjustment support that is required during uncertainty and unpredictability. GPs have been rated as the most important

source of information in health and illness and have the power to reinforce a change of attitudes to healthcare (Coulter 2002).

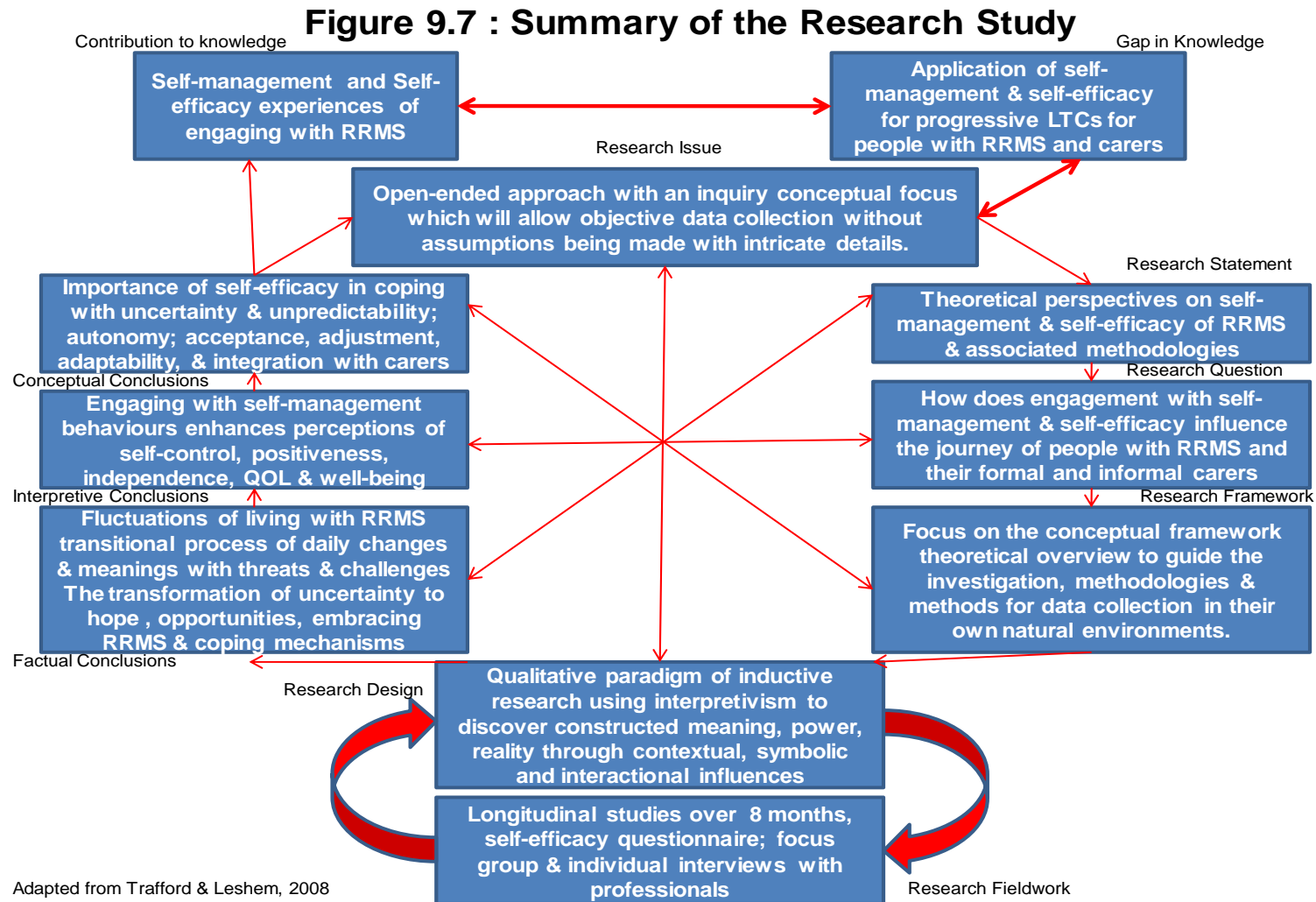
The people with MS and their informal carers want to be more involved in decision-making and making choices based on the information and knowledge that they have and that are provided around the area of choice. The professionals involved in the research have not received any training or developments to help them to cope with more partnership working, joint decision-making or more power being given to patients. There have been discussions within most of the interviews regarding the difficulties encountered due to the lack of training and development for people with RRMS, their partners/carers and the professionals. Expressed concerns feature around information and knowledge being withheld in order to maintain professional power; fear and risks of some decisions that people are taking based on inadequate information; differing expectations in consultations; partners being ignored and expected to take a back seat; difficulties or unwillingness to explain complex terminology; professionals only seeing people annually and not really knowing them or their condition; threats of seeing expert patients who have more knowledge of MS than the professionals; and not sharing knowledge, experience and expectations of other people with MS which might be helpful to others.

There should be the development of a personalised plan for people with RRMS which allows them with their partner/carer to set out their own goals and targets which are related to coping with their MS. This could set out their own independence, self-management and coping strategies which could be updated and shared with both formal/informal carers as and when required. Most of the emphasis and developments have been on professional personalised care plans, illness trajectories, care pathways and professional care records which are written by professionals and in limited cases are shared with patients. The researcher proposes that real consideration should be given to a personal plan with support and development by professionals to enhance the self-management and self-efficacy of people with RRMS. This plan would also be useful to families in setting out the boundaries and support that they can provide to the person with MS.

The three groups of research participants did have determination, purpose, willingness and ability for self-management and self-efficacy to work but there were different agendas, levels of understanding and no clear mutual purpose to work together. Structures and systems should be implemented to make this work for the benefits of people with LTCs, their families and health and social care professionals. Collaborative working through an integrated care management system controls, monitors, reviews and directs care in the most effective manner, and recommends the most appropriate treatment in the most efficient environment (Wilson 1997). This enhances patient and staff satisfaction through providing outcome based quality and patient focused care.

Figure 9.7 provides a summary of the research study in terms of the personal journey of the researcher and identifying the key elements of the project. Trafford & Leshem (2008) describe this as the magic circle which is a system of interconnected parts through the sequences of the research actions including the summaries of the conclusions and the contribution to knowledge.

There has been great joy and satisfaction that my research has been the lever to allow the voices of the research participants to be heard in sharing their stories, knowledge and experience. There is also sadness in bringing this research to a close as I have personally learned so much from the people with RRMS and their partners/carers. I shall continue to share their stories and experiences by disseminating the research findings through the writing of papers and reports, presentations and discussing my findings with the MSS. Through the metaphor of the roller coaster ride and the main themes of Challenge, Transition and Transformation there is a clear understanding of the lives and self-control, independence and self-management of people with RRMS. The readers of this thesis can learn about the MS journey and how it can affect personal lives and health and social care practice and be shared as experiences of living with a progressive long term condition. The influence of engagement in self-management therefore, has important implications for people with RRMS, their partners/carers and the professionals working with MS.



The key message throughout this research and the main contribution to knowledge is in revealing that people with RRMS go through a process of phases of integration through changing their world with new understandings, beliefs and the importance of engaging with self-management and self-efficacy; while endeavouring to reach outcomes of maintaining independence, self-control, positiveness, mastery and quality of life.

This thesis placed the voice and experiences of people with RRMS, their formal and informal carers at the heart of the MS trajectory. This focus enabled the development of personal journey maps around the importance of engaging with self-management and self-efficacy to orchestrate more individual choice and decision making through partnership working. The different perspectives, experiences and knowledge gained enabled changing priorities for practice, policy and reality. This research study has attempted to increase the degree of alignment between the everyday lives of people with RRMS, their partners/carers and the professionals to work more collaboratively through joint decision making, education and research. Further research could be undertaken to build upon these findings and to bring greater congruence to the management of progressive LTCs.

Appendix I
Self-Management Support

Appendix I

Self-management Support

The use of self-management support further develops the engagement of people with LTCs by discussing the support that is available to help those people who want to be involved in their own self management through skills/confidence development and focussing on their lifestyle changes and health outcomes.

Self-management support refers to the facilities that health and social care services provide to enable patients to enhance the management of their health. It includes patient education, the collaborative use of a wide range of behavioural-change techniques to foster lifestyle change, the adoption of health-promoting behaviours and skill development across a range of LTCs (Farrell et al. 2004). The main aim of self-management support programmes is to prepare patients to engage with medical management, maintain life roles and to manage negative emotions such as fear and depression by offering patients the opportunity to acquire the necessary knowledge, skills and confidence to deal with disease related problems (Goldberg et al. 2003, 2004). The CDSMP and EPP and Disease specific programmes such as the MS Getting to Grips Course are all examples of these support programmes.

Other sources of information for self-management support include Telemedicine, or interactive health communication applications (IHCAs) as that is sometimes referred to, are significant technological advances which may have a role to play in facilitating the implementation and delivery of self-management within health care. An important issue is how people with LTCs, their partners/carers and families respond to using such technologies. Also the health and social care professionals in terms of using the interventions with people with MS, their partners/carers and their families. Understanding the factors that lead to the successful adoption and integration of these technologies into routine practice is critical.

Applications of individual behaviour change domains such as knowledge, motivation and goal settings have been identified by Michie and colleagues will aid this understanding (Michie et al. 2005). Similarly application of the Normalization Process Model (May 2006; May et al. 2007) and WISE (Whole System Informing Self-Management Engagement) Model (Kennedy and Rogers 2001) are likely to assist in understanding the process of integration within broad social and organisational contexts. The WISE systematic model approach to self-management advocates three interrelated levels: patient self-care needs, experience and knowledge to the management of their condition, engaging and involving health and social care professionals and the fit with services and access arrangements of the healthcare systems. This includes ways to enhance the patient's capacity for self-care through information processes, and how professional practice and service organisation can be modified to support self-management practices. The WISE (Whole System Informing Self-management Engagement) model has a wider conceptual approach to diffusion of innovation, focusing on appropriate information and improved access to services for patients, and training for health care professionals in patient-centred consultation skills. The framework was informed by a view of self-management practices as potentially being both enabled and constrained by the interactions that take place between individuals and health professionals in health service settings (Rogers et al. 2005).

Self-management support in general aims to change the behaviour of people with LTCs in some way to manage their symptoms and lifestyle in order to maintain their condition and prevent further deterioration where possible and to involve them more in their own care process. The way that knowledge and information is shared with people with LTCs can determine how they use this in order to change the way they do things, their levels of motivation and self-determination. In the behaviour paradigm information and knowledge is shared in a passive way where knowledge is seen as remembering things and understanding in ways of seeing patterns or how things fit in to each other. Whereas in the cognitive paradigm learning is active and knowledge is about receiving new information on which different things can be done to reveal a

relationship between problems and the person can decide what is best or works for them.

To date self-management support initiative for patients (education programmes) and healthcare professionals (education and training) have largely been segregated, with no overarching coordination between the two and no recognition of their potential mutual reinforcement (Rogers et al. 2005). This is problematic, given the important role that the patient-health care professional relationship plays in enabling and supporting self-care, providing a critical juncture for exchange of information, and decision making (Kennedy et al. 2005). Research undertaken by Thorne et al. 2004 emphasised the importance of patient–professional communication as being a critically important element of effective chronic illness care but found that the ability of health care professionals to engage in effective communication during a consultation can reinforce or discourage health actions that maximise a person's capacity to live positively with a chronic condition. The importance of people with LTCs engaging in self-management and health and social care professionals working collaboratively with them is imperative for self-management support to be effective.

Self-management support involves a patient-centred collaborative approach to care to promote patient activities, education and empowerment (Goldstein 2004). It changes the role of the health and social care professionals from delivering didactic education and instructions to trying to engage more with patients and to empower them to be more involved in their condition management, decision-making and choices. It includes patient involvement in increasing their knowledge and use of information through education and technology to improve their symptom management, lifestyle, quality of life through the adoption of behaviour change techniques and interventions. Self-management support can be provided to individuals, groups, through computer based interactive programmes, e-mails, telemedicine and by telephone. Self-management support has been identified as the area of disease management that is least often implemented and the most challenging to integrate into usual care (Glasgow & Strycker 2000).

Appendix II

Information for research participants

Consent Forms

GP Information

Information for Research Participants

A Research Project

Working together to improve the service we provide for people with multiple sclerosis.

Seeking Volunteers



Inviting all health and social care staff, who are involved in caring for people with multiple sclerosis, to talk to me about their experiences of being involved with North Tyneside Neurological Rehabilitation Services.

If you agree I will ask you if you would agree to take part in focus group interview and to help me select people with relapsing remitting multiple sclerosis and their partners/carers for case studies.

Detailed information, including a copy of the research proposal, will be presented at the first focus group interview session.

In the meantime you can contact: Jo Wilson on 07702 729169 or email at: jo.wilson@unn.ac.uk

30th November, 2007

Dear

**Re: Self-management and self-efficacy for people with
multiple sclerosis. An Expression of Interest**

**By now you should have received detailed information about
the above research project being undertaken by North
Tyneside PCT and Northumbria University.**

**If you would like to take part please complete and return the
response form to Jo Wilson. I will then contact you by phone
to arrange the date, time, venue for the interview**

Yours sincerely,

**Ms Jo H Wilson
Doctorate Student**

Please tick:

I agree to take part in the taped focus group interview and individual interviews, I understand that what I tell you will be confidential and the final report will not include my real name.

Print Name.....

Signature

Date

**Information sheet for people with Multiple
Sclerosis and their partner/carer**

**What differences have you and the support of
your health and social care team and
partner/carer made to the management of
your multiple sclerosis?**

**A Research Study
To listen to your views**

Who am I?

The Researcher:

Ms Jo Wilson who is undertaking research as part of a doctorate degree at the Northumbria University. My background is in nursing but during the research process I will not be directly participating in your care.

I would like to invite you and your partner / carer to take part in my research study. Before you decide it is important for you to understand why the study is being carried out and what it will involve for you and your partner/carer. Please take time to read the following information carefully and discuss it with others if you wish. Ask me if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

What is the purpose of the study?

The journey of living with the diagnosis, the explanation of the multiple sclerosis and the treatments, needs to be understood, if partnerships are to be built between people with the condition and their health and social care professionals. I would also like to talk to your partner/carer to discuss how they are involved in your care and what their experiences have been in working with health and social care professionals.

I would like to find out from you, **your own views** and **experiences** of living with and coping with multiple sclerosis. Also the views of your partner

/carer, with your permission, in being with you and involved in the journey.

Why have you been invited?

This is because you have multiple sclerosis and are living in North Tyneside where the study is being undertaken. I would like to find out about what life has been like for you, since you have been diagnosed with multiple sclerosis, in particular how you manage your lifestyle and about the support you receive from your health and social care professionals. I will be asking other people with multiple sclerosis and their partners /carers to take part who all have different support needs.

Do you have to take part?

No. It is up to you to decide whether or not to take part in this study. I am giving you this information sheet to help you make that decision. It is important to remember that if you do decide to take part, you are free to change your mind and withdraw from the study **at any time**, without giving a reason. A decision to withdraw at any time, or a decision not to take part, will **not affect** the standard of care you receive within North Tyneside PCT.

What will happen if you take part?

I would like you and your partner/carers to be individually interviewed by me for approximately 1 hour each month over about an 8 month period.

These interviews will allow you to confidentially talk about your individual experiences

I would like you to share with me the things that have been good for you in learning how to live and manage your multiple sclerosis. Also what has not been so good for you and how these things could be further developed to help you and other people.

I would like your partner/carer to tell me separately about their experience of supporting and understanding multiple sclerosis. These interviews will be confidential and identities will not be disclosed.

In studying how people with multiple sclerosis adjust to living with their condition I can study the impact this has on your lifestyle, quality of life and day to day living.

This will provide you with an opportunity to:

- let me know how you feel that the care and support that you and other people with multiple sclerosis could be further developed.
- be included as one of the most important people in the decisions about the services you require
- help to plan for the future so that health and social care professional working in partnership can do their best for all people who suffer from multiple sclerosis
- to provide consent to be involved in the study, to allow me to talk to your healthcare

professionals and to have access to your ongoing care plans and goals

Where will we have the interviews/discussions?

- That's up to you and your family. I can come to your house and chat to you or I can have a chat with you while you are at the neurological rehabilitation centre.
- If you allow me, I will tape our conversation so that you and I can remember what you have told me. The tapes of these discussions, and any other information I gather, will be stored securely and will remain strictly confidential.

What are the possible disadvantages of taking part?

You will be asked to give up some of your time to take part in the discussions. I will, however, arrange it for a time that is convenient for you. During the discussions you will be asked to think and talk about your experiences of being diagnosed and living with your multiple sclerosis.

What are the possible benefits of taking part?

There may be no direct benefit for you personally from taking part in the study. However, by listening to people talking about their experiences of living with multiple sclerosis and their views about self-management, this will assist in better

understanding their needs along the care management journey.

Will your taking part in this study be kept confidential?

Yes. If you consent to take part in this study, I am required by the Data Protection Act (1998) to ensure that any information about you will be treated with the strictest confidence. Also any discussions with your partner/care will be kept confidential and not shared with you or anyone else and their identity will also not be disclosed. This means that the audiotapes from your and your partner/carers interviews and the transcriptions of these tapes and any notes I have made, will be stored securely and your names will not be written on any of these items. Your names will not appear in any reports or documents resulting from this study.

The only exception to this confidentiality is if you tell me, the researcher, about any criminal activity, harm or danger, in which case the researcher has a duty of care to pass this information to the PCT management team.

What will happen to the results of the study?

The main findings of the study will be shared with the professionals and people with multiple sclerosis and their partners/carers in two separate groups. This will allow both groups to see the each others viewpoints and any differences between the groups.

The results of the study will be used to inform service providers and researchers about the self-management and support requirements of people with multiple sclerosis. This may be done through publishing the findings in academic and professional journals and by speaking at conferences and other events. Everyone taking part in the study will be sent a summary of the results of the study and how these are being used.

What happens if you do not want to take part?

If you do not want to take part in the project that's fine, it will not make any difference to your care provided by North Tyneside PCT. Just let me know that you are not interested in being involved in the study.

How to contact me

You may have some questions about the study; you might not want to talk to me or you may decide that you do not want me to put what your responses in the report, which is absolutely fine. You can contact me at anytime, before or after I see you.

Contacting Jo Wilson

Telephone 07702 729169 Monday to Friday

Email jo.wilson@unn.ac.uk **anytime**

Thank you for helping me with my study

How to Complain

I hope you have no cause for complaint, but should this be the case, please discuss this with me in the first instance. We will then make it known the Complaints Officer of the North Tyneside Primary Care Team. Who will do their utmost to resolve the problem.

If you are not satisfied with this response, a formal written complaint should be made to Mr C Reed, Chief Executive.

North Tyneside PCT has a formal complaints policy that will be followed in the case of all written complaints. A copy of this is available from your Care Team.

If you need to make a formal complaint, please contact:

Mr C Reed, Chief Executive
North Tyneside PCT
Equinox House
Silver Fox Way
Colbalt Business Park
Newcastle Upon Tyne
NE27 0OJ

Tel: 0191 2919292

OR

National Care Standards Commission
No 1 Hopetown Studios,
Brinkburn Road,
Darlington,
Co Durham
DL3 6DS

Tel: 01325 371720

Consent forms



North Tyneside



Primary Care Trust

CONSENT FORM

Title of Project: Self-management and self-efficacy for people with multiple sclerosis.

Agreement to take part in the study - Longitudinal Study

Name of Researcher: Ms Jo H Wilson

**Please initial each
of the numbered
items below**

1. I confirm that I have read and understand the information sheet dated 2nd October, 2007 (version.2) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.
2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected.
3. I agree to my partner/carer being approached to be involved in the study
4. I understand that the researcher may want to discuss my care plan and goals and I give permission for her to have access to my records.
5. I agree to my GP being informed of my participation in the study
6. I agree to take part in my case being studied over 8 months in the above study during which time I will be asked to talk about only my own experiences.
7. I agree to our discussions being tape recorded by the researcher

Name of Patient Date Signature

Name of Person Date Signature
taking the consent

CONSENT FORM

Title of Project: Self-management and self-efficacy for people with multiple sclerosis.

Agreement for partner/carers to take part in the study

Name of Researcher: Ms Jo H Wilson

**Please initial each
of the numbered
items below**

1. I confirm that I have read and understand the information sheet dated 2nd October 2007 (version.2) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.
2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected.
3. I agree to take part in being interviewed as part of the above study.
4. I agree to my interview being audio taped by the researcher.

Name of partner/carers Date Signature

Name of Person Date Signature
taking the consent

GP Information



Dear Dr

Your patient, XXX, has agreed to take part in my research study on self management by people with relapsing remitting multiple sclerosis. He/she has given me permission to contact you and let you know of their participation. I enclose further information of what this will involve and if you require further information please contact me.

Yours sincerely

**Ms Jo H Wilson.
Doctorate Student.**

A Research Study in collaboration with North Tyneside PCT Long Term Conditions Service and Northumbria University.

Information Sheet for GPs

Who am I?

The Researcher:

Ms Jo Wilson, RGN RM RSCN who is undertaking research as part of a doctorate degree at the Northumbria University.

Title of the Project

Self-management and self-efficacy for people with multiple sclerosis.

Definition from the Department of Health 2006

"Self-management is all about individuals taking responsibility for their own health and wellbeing. This includes staying fit and healthy, both physically and mentally; taking action to prevent illness and accidents; the better use of medicines; treatment for minor ailments and better care of long term conditions" (DH, 2006).

Aims of the project

To determine, from the perspectives of people with relapsing remitting multiple sclerosis and the health and social care staff working with them:

- To develop an understanding of the engagement process and the different levels of involvement in self-management undertaken by people with multiple sclerosis.
- To increase understanding of the concepts and attributes of self-management and self-efficacy, the Department of Health (DH, 2006) definition will be considered as one amongst multiple other possibilities that will be explored, from the construct and experience of professionals, people with multiple sclerosis and their partners or carers.
- What are the factors that help to develop a willingness and ability to:
 - take control and be engaged in self-management
 - health promotion
 - lifestyle management

Research Methods

The research will be undertaken using case studies with a total of six people with relapsing remitting multiple sclerosis and their partners/carers which will be studied over a minimum eight month period to discuss their levels of engagement, self-management and self-efficacy over time. Also by the use of focus groups and individual interviews of professionals from the neurological rehabilitation and primary care teams working with people with multiple sclerosis.

Research Findings

The main findings of the study will be shared with the professionals and people with multiple sclerosis and their partners/carers in two separate groups. This will allow both groups to see the perspectives, processes and outcomes from each others viewpoints and to reduce any gap analysis.

Contact for further information:

Ms Jo H Wilson (Doctorate Research Student): 07702 729169 or jo2.wilson@unn.ac.uk
Room H214 School of Health, Community and Education Studies Coach Lane Campus, East Northumbria University Newcastle upon Tyne NE7 7XA

Appendix III
Research Interview Topic Guides

Topic Guide for Focus Groups

Introduction and background

"Self-management is the individual's ability to manage the symptoms, treatment, physical and psychosocial consequences and lifestyle changes inherent in living with a long term disorder". DH

Process Map the typical patient journey for a person with multiple sclerosis.

1. Views and beliefs on self-management

- Do you feel that people with multiple sclerosis are interested in self-management?
- Are the DH expectations realistic?
- What are your expectations?
- Do you believe self-management can relieve some of the work pressures of health and social care staff?
- How do you promote empowerment and maintenance of their independence for people with multiple sclerosis?
- Does self-management have any implications for the improvement of quality of life and appropriate utilisation of services?

2. Models of self-management in use

- Can you describe which models and levels of self-management that you use to fit within your existing infrastructure and services?
- Do you feel that the models described personalise and integrate the care processes?
- How do you support the people with MS and their carers in terms of the unpredictability and uncertainty of the condition?
- Describe how you are able to get support and coordination of care for your patients with multiple sclerosis?

3. Enhancement of knowledge, independence and self-efficacy

- Are people with multiple sclerosis interested in their conditions in a way that enables them to participate fully in society?
- How do you build up confidence and belief that the people with multiple sclerosis can do things to help themselves?
- Do you feel that you are able to do as much as you can to make the person with MS as independent as possible?

4. Support for the people with MS and their families

- List some of the support, including voluntary and community that is available within North Tyneside for people with MS and their families?
- Describe how you are able to access the support and make the patient and family aware of what is available?

5. Partnership working

- To what extent do you feel you are able to work in partnership with people with MS?
- Are you able to work in partnership across health and social care and other organisation to fully facilitate case management?

6. Suggestions for service improvements

**Topic Guide –Discussion areas for Longitudinal Studies for People with Multiple Sclerosis and their Partners/Carers
(Areas will be worded to People with MS and their partner/carers appropriately)**

Perceptions and knowledge of long term condition

- Perception and feelings of having MS and changes that have occurred during the journey of the illness.
- Feelings developed in the knowledge and expertise in the daily management of your MS
- Ways they have learnt to cope with the uncertainty and unpredictability of MS
- Changes in terms of activities and lifestyle being diagnosed with MS

MS care

- Knowledge of MS and the support that is available to them
- Encouragement to engage in understanding and managing MS
- Effects of MS on everyday activities and lifestyle
- Support given by health and social care professionals in teaching, counselling, directing and coordinating activities
- Self-management and prevention of complications of MS
- Methods of coping with symptoms and changes of MS in terms of remissions, exacerbations or progression of the disease

Self management and locus of control

- Factors that influence the patient's and family's ability to manage and deal with MS and its unpredictable, uncertainty and fluctuating course of events.
- Coping and adapting to MS and any issues that impede taking control
- Empowerment and confidence in carrying out self-care and reach any self goals
- Maintaining physical and psychological health and well-being
- MS person and partner/carers goals in dealing with MS and with any current problems and goals for the future – current activity level and the level of functioning
- Prevention of complications and minimising any disabilities by feeling empowered to take an active role in decision-making
- During hospital or rehabilitative care admissions feeling of wishes to direct and be able to self-care

- Involvement in setting up care pathway and goals for ongoing activities
- Willingness and ability to take some control and be involved in self-care

Partnership working

- Encouragement of working in partnership with formal care providers
- Encouragement to be involved in joint decision-making and setting own goals and outcomes
- Views of the patient and partner/carer on keeping the MS under control and minimising the effect on the person's and their family lives

Partner / Family Life

- Impact or major changes in the your family relationship
- In terms of managing MS are there any activities that you avoid as they make your symptoms feel worse or less controllable
- Coping with the uncertainty and unpredictability of the condition and the effect on the person with MS
- Feelings of interference with ability to manage your MS e.g. social support, resources, other health problems in the family
- Changes that have occurred in your home which promote or impede your ability to live as normal a life as possible.

The longitudinal studies with people who have MS and their partners and cares will cover the areas over the 8 months which are appropriate for their relapsing remitting MS.

Appendix IV

Data Analysis Processes - Data Examples

- a. Nvivo Coding Examples**
- b. Sample of Synthesizing the Data**
- c. Sample of Analysis Maps**

People with MS 17.02.2009.nvp - NVivo

File Edit View Go Project Links Code Tools Window Help

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Code At

Look for: Search In: Free Nodes Find Now Clear Options

Free Nodes

Name	Sources	References	Created	Modified
Self-determination	27	49	08/05/2008 11:1	18/02/2009 09:30
Self-control and Self-efficacy	45	210	08/05/2008 11:1	18/02/2009 09:39
Risk	15	28	24/09/2008 11:4	17/02/2009 17:10
Referral for investigations	2	5	08/05/2008 11:1	14/05/2008 17:43
Recognition of Relapses and Remissions	24	48	08/05/2008 11:1	17/02/2009 17:44
Quality of Life	6	14	23/09/2008 16:0	18/02/2009 09:39
Professional Support	21	68	08/05/2008 11:1	18/02/2009 09:31
Private Healthcare	3	7	08/05/2008 11:1	02/12/2008 15:47

Interview One MS 3

erm first I thought I'd just been lying awkwardly at night and erm mebbies trapped a nerve or felt as though that erm something wasn't right but I wasn't sure what was going on. Erm pins and needles in my hands erm especially, it was mainly to do with my right side, but because I sleep on the left side I couldn't understand why I was hurting on my right side as much as it was. Erm and I contacted my GP and made an appointment within two days, obviously my GP erm saw Dr Vivien Heaton, and she basically had a look and she did some tests, she did my blood pressure, she had a look at my eyes and she had a look at my hands and she got me to stand up and walk around and she noticed there was a significant drop in my right leg, I was dragging my right leg, erm and she organised some tests to be done and she wanted to refer me to a consultant.

Jo: Had you not noticed that you were dragging your right leg?

I didn't no, I didn't notice. Erm she organised some tests to be done, some blood tests and things and she asked if it was okay if she referred me to the RVI. Erm and she didn't sort of give me any indications as to what it could be, she seemed as puzzled as I was to what was going on at that time. Erm and it was over the next sort of two or three weeks that I started havino erm referrals to

78 Items Nodes: 25 References: 86

Line by
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Professionals MS 22.1.2009.nvp - NVivo

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Tree Nodes

Name	Sources	References	Created	Modified
MS Person Pathway	10	91	08/12/2008 13:02	08/12/2008 13:02
Complimentary Therapies	3	8	08/12/2008 13:14	08/12/2008 13:14
Depression and Cognitive Issues	4	9	08/12/2008 13:13	08/12/2008 13:13
Expert and Getting to Grips	4	19	08/12/2008 13:15	08/12/2008 13:15
MS Nurses Support	3	7	08/12/2008 13:07	08/12/2008 13:08
Referral Patterns	10	31	08/12/2008 13:07	08/12/2008 13:07
Support Services	7	46	08/12/2008 13:10	08/12/2008 13:10
Voluntary Support	2	3	08/12/2008 13:08	08/12/2008 13:08
MS Persons' Journey	13	104	08/12/2008 12:52	08/12/2008 12:52
Carer Support	7	20	08/12/2008 13:14	08/12/2008 13:15
Diagnosis	6	35	08/12/2008 13:12	08/12/2008 13:12
Employment Support	1	3	08/12/2008 13:13	08/12/2008 13:13
Information for People with MS	9	62	08/12/2008 13:12	08/12/2008 13:12
MS Patient Reviews	8	32	08/12/2008 13:05	08/12/2008 13:05
Ostrich Syndrome	1	3	08/12/2008 13:09	08/12/2008 13:09
Quality of Life	5	23	08/12/2008 13:06	08/12/2008 13:06
Symptoms	7	30	08/12/2008 13:11	08/12/2008 13:11
Self-management and self-care	11	73	08/12/2008 12:53	08/12/2008 12:53
Risk Taking	2	12	08/12/2008 13:11	08/12/2008 13:11
Self-efficacy	10	46	08/12/2008 13:10	08/12/2008 13:10

24 Items

Axial
Coding
Example
with Data
Groups
to enable
Selective
Coding

Professionals MS 22.1.2009.nvp - NVivo

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Tree Nodes

Name	Sources	References	Created	Modified
Communication between Professionals	9	39	08/12/2008 12:53	08/12/2008 13:09
Empowerment	9	44	08/12/2008 12:53	08/12/2008 12:53
MS Person Pathway	10	91	08/12/2008 13:02	08/12/2008 13:02
MS Persons' Journey	13	106	08/12/2008 12:52	30/08/2009 18:15
Self-management and self-care	11	73	08/12/2008 12:53	08/12/2008 12:53

Perspectives

This interview involves a person who is a Doctor and also has MS and therefore covers both the professional and the patient perspective.

I think being medically trained and then developing symptoms you that think you must be some type of hypochondriac, because you do think and hear so much about things. I developed numbness in my feet and in my hands and I was thinking of erm the numbness what could this be and I was thinking that it could be this or it could be that. I thought it might MS and erm I was a bit worried about it because I thought I could not think of anything else it would have been other than MS. I was also the right age and the right gender and the rest of it. And I went to the my GP at the time sort of just to know about it, and sort of just discussed it with some of my friends who said why don't you go and see someone and then the GP did the basic tests. Basically I remitted from that particular sort of probably the first symptoms and they got better within 6 weeks and then looking back I had a period of feeling really great, really absolutely fantastic God I feel great wonderful and then looking back I realised I was getting better from that relapse.

24 Items Nodes: 2 References: 5 Line: 13 Column: 64

Selective
Codes
and
Memo
Example

b. Sample of Synthesizing the Data -The Day of Diagnosis

Interview	Receiving the diagnosis	Range of responses, elements, properties, dimensions etc.
MS 1	<p>Interview 1 The Consultant said well what I can tell you is, just straight out with it, you've got MS and I'm thinking MS what is that. I had no idea what it was, never heard of it at all</p> <p>Interview 1 The consultant gave me some very, very wise advice, from that appointment, I presume, I've kept it in my head every since. You know it was erm if you want to go home and you want to feel sorry for yourself and you don't want to do your shopping and you don't want to walk your dog and you don't want to drive your car I can assure you you'll be in a wheelchair in three weeks. You remain in that positive mind, you do everything you always did before, drive the car, go to work, do your shopping, walk your dog, you'll be fine, and I was up until last year when I finished.</p> <p>Interview 1 I could have cried me heart out, I could have been quite hysterical, even though I didn't know what it was I knew it was serious, but he did state I had a very mild form.</p> <p>Interview 1 Well I was absolutely fine, I came home and I rang the MS Society and erm as soon as I was out of his room I broke me heart. I knew it was serious but as I say I didn't know what it was I had no idea.</p> <p>Interview 1 I rang the MS Society when I came home and they sent loads of leaflets and things like that erm but from then on really I suppose, because I carried on working and I did all he said</p> <p>Interview 1 the one thing the consultant did say to me was when you get a symptom, you possibly will get a few symptoms over the next few years he said from the day it comes to the day it gets bad, to the day it gets worse, to the day it gets better it'll be three weeks, I'm telling you. And I've always worked it out on that and it always has been, up until the last year. I would say probably it's a bit longer now.</p> <p>Interview 1 I had to be positive, had to be, and the consultant told me that, he said you've got to stay positive up there. Don't ever say to yourself why me. He said because that's just irrelevant it's happened that's it. So I never ever have</p> <p>Interview 5 I remember in the room sitting there with my husband when the Consultant just came out with it, you know he was very matter of fact and he</p>	<p>You have MS. No idea what it was and had never heard of it</p> <p>Do not feel sorry for yourself Remain positive</p> <p>Cried – I knew it was serious Mild form</p> <p>Rang MSS Broke my heart</p> <p>Information from MSS</p> <p>Day of symptoms it will get worse but will last only 3 weeks in total but will only be 80% return to what it was before Feels longer now</p> <p>Positive – Never say "Why me?"</p> <p>Consultant just came out with it and we left. I was in shock.</p>

	<p>just said IT. I remember saying well thank you very much and we left.</p> <p>Interview 5 And when we were in the room prior to this I remember not being, thinking not being able to look round and look at my husband because I was going to cry. Because I knew it was something serious but I had no idea what it was, I had to start ringing the MSS and things like that for them to start sending me leaflets. Probably after that, which was the time that I tried to block it out because people had started to, my family and my husband had started to accept it that this is what I had and there was no cure to it.</p> <p>Interview 8 Because I was frightened to look at my husband because I knew that I would burst into tears and I remember starting to burst into tears on those stairs. I was saying what is MS? What have I got? I remember it so well as if it was yesterday it is so fresh in my mind and I will never forget it.</p> <p>Interview 8 I have been off for 4.5 months from when I first felt unwell and up until the diagnosis because I was really upset that it had taken that time and I could not believe I had to be off work for so long. I was so upset that it had taken 4.5 months I could not believe it and then he just came out and said you have got MS.</p> <p>Interview 8 The diagnosis does stick in my mind because of what he said to me at that time and how I felt about it all.</p> <p>Interview 8 Then he said if you do not continue with your life going to work, doing you're shopping, walking your dog and driving your car then I can guarantee that you will be in a wheelchair in 3 weeks.</p>	<p>I tried to block it out. There is no cure</p> <p>Frightened Burst into tears It is fresh in my mind like yesterday and I will never forget it.</p> <p>Upset as was absent from work for 4.5 months</p> <p>Clear in her mind How I felt about it If you do not continue to live life to the full you will end up in a wheelchair in 3 years</p> <p>Need to normalise my life and keep going through this transition</p>
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Identifying dimensions and properties of groupings and concepts
– across all 6 people with RRMS

The day of diagnosis	Coping strategies	Higher order categorisation
<p>You have MS and it was left at that</p> <p>Upset & crying – frightened, shocked, frustrating & scared</p> <p>Relieved it was not a brain tumour, cancer or stroke</p> <p>Validation of the symptoms not a hypochondriac or malingerer</p> <p>Relieved that not going to die as MS does not kill you</p> <p>Good news / bad news</p> <p>Knew there was something wrong as they knew their own body</p> <p>Feeling isolated and helpless</p> <p>Day of diagnosis very clear in their minds like yesterday</p> <p>Did not know what is was</p> <p>Remain positive and to not give in to it as you will go downhill very quickly</p> <p>MSS for information</p> <p>WHY ME and denial</p> <p>Effect on partner and family</p> <p>Fluctuating complex experiences & being swept along</p> <p>Tried to block it out – disbelief</p> <p>Cannot fight it but also cannot lie down and just take it</p> <p>Trying to keep things normal</p> <p>Length of time to diagnosis</p> <p>3 out of 6 feared it was MS and knew before they were actually told</p> <p>Trying to locate past causes in childhood</p> <p>Coping with the symptoms and relapses</p> <p>Hard to accept</p> <p>Recognise limitations and learn the lessons if you overdo things you pay for it – MS bites back</p>	<p>Blunt way they were told and no explanations given</p> <p>Hiding how they felt until out of vision of Consultant</p> <p>Relieved and able to move on</p> <p>Validation that something is wrong and working out what to do</p> <p>Not going to die – relief</p> <p>Know own body and when things are not right</p> <p>Isolation & helplessness</p> <p>Clarity</p> <p>Most did not know what MS was</p> <p>Positiveness & control</p> <p>Denial</p> <p>Effects on partner & family</p> <p>Complex & dynamic</p> <p>Disbelief</p> <p>Cannot fight it</p> <p>Normalising</p> <p>Time to diagnosis</p> <p>Fears of it being MS</p> <p>Previous potential causation</p> <p>Coping mechanisms</p> <p>Acceptance</p> <p>Limitations and learning the lessons</p> <p>No cure or treatment to take it away</p> <p>Independence, control & self determination</p> <p>Physical limitations</p>	<p>Diagnosis of RRMS</p> <p>Feelings:</p> <ul style="list-style-type: none"> - Feelings/perceptions - Relief, validation & not going to die - Self-identity – know own body and fears of what others might think - Sense of loss of self - Fears of dependence - Fears of wheelchairs - Denial/disavowal - <p>Coping:</p> <ul style="list-style-type: none"> - Utilising identified coping mechanisms - Need to be positive, in control, independent and have self-determination - Coping by symptom control & managing physical limitations - Manage the uncertainty & unpredictability - MS bites back so have to self pace - Carry on as normal - Overcome the challenge to person with RRMS and their family

<p>Saddled with MS, no cure and no effective treatment just symptom control</p> <p>Independence and control through self-determination</p> <p>Difficult to understand what was happening physically</p>	<p>Self-management and self-efficacy</p> <p>Fluctuating uncertainty and unpredictability</p>	
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Lack of control Vision for the future Fight MS Early Symptoms Quality of Life Fear of the unknown Adaptation Grief
 Driving effects Coping Mechanisms Adjusting to Life with MS Telling People about My MS Denial, head in ADLs
 Lonely & isolated Goals & Targets I am not going to give in There is No cure the sand, ostrich syndrome Jovial
 RISK Cannabis Fears & Concerns Anger and frustration Private Healthcare Loss of Self-esteem Complimentary Therapies Turbulent TIME
 DMTs Fear of Wheelchairs MS Investigations Hope & Desperation Roller Coaster Vulnerable & Insecure
 Contingence Issues Visual Problems MS Bites Back Powerlessness Mobility Issues Roller Coaster
 Pacing Yourself Path of no return Regaining Control Learning the Lessons MS Lifestyle Attention to detail Steroid Therapy
 Disruption to Life I have MS but MS does not have me Positive Feelings Uncertainty & Unpredictability
 Fatigue & Overdoing things Fears caused by symptoms Challenge Cognition & Depression Feeling Loss & Lost FALLS
 Work Related Immediate Admission I am not a malingerer or a hypochondriac MS Information & Knowledge
 Falls due to MS Understanding MY MS MS is a huge challenge I am always positive & Confident Changed my self perception Living on the edge Relief at Diagnosis and taking symptoms seriously
 MS Information & Knowledge I really need a job



Appendix V

Self-Efficacy Questionnaire and Qualitative Analysis of Responses

a. MS Self-Efficacy Scale

b. Qualitative Response Summaries MS1- MS6

The MS Self-Efficacy Scale

Instructions: For each of the statements below please circle one answer to each question to indicate your level of agreement or disagreement, for yourself, at the present time.

Question 1

I am confident when meeting new people and going to new place

Strongly disagree	Firmly disagree	Disagree	Agree	Firmly agree	Strongly agree
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Question 2

I find that the things I do during the day make me feel happy and satisfied.

Strongly disagree	Firmly disagree	Disagree	Agree	Firmly agree	Strongly agree
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Question 3

I sometimes have thoughts about whether my condition will get worse.

Strongly disagree	Firmly disagree	Disagree	Agree	Firmly agree	Strongly agree
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Question 4

Sometimes I feel embarrassed in public places.

Strongly disagree	Firmly disagree	Disagree	Agree	Firmly agree	Strongly agree
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Question 5

I like not having to (or the thought of not having to) go to work

Strongly disagree	Firmly disagree	Disagree	Agree	Firmly agree	Strongly agree
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Question 6

Planning for the future helps me cope with my illness.

Strongly disagree	Firmly disagree	Disagree	Agree	Firmly agree	Strongly agree
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Question 7

I can keep my MS from interfering with time spent with my family and friends.

Strongly disagree	Firmly disagree	Disagree	Agree	Firmly agree	Strongly agree
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Question 8

I have as much independence as I feel I need.

Strongly disagree	Firmly disagree	Disagree	Agree	Firmly agree	Strongly agree
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Question 9

Sometimes I feel inadequate as a person because of my condition.

Strongly disagree	Firmly disagree	Disagree	Agree	Firmly agree	Strongly agree
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Question 10

I often feel a failure in things that I try and do.

Strongly disagree	Firmly disagree	Disagree	Agree	Firmly agree	Strongly agree
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Question 11

There are things that I can do to help control my fatigue.

Strongly disagree	Firmly disagree	Disagree	Agree	Firmly agree	Strongly agree
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Question 12

I often feel that MS controls my life

Strongly disagree	Firmly disagree	Disagree	Agree	Firmly agree	Strongly agree
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Question 13

I can usually do what I want to do when I want to do it.

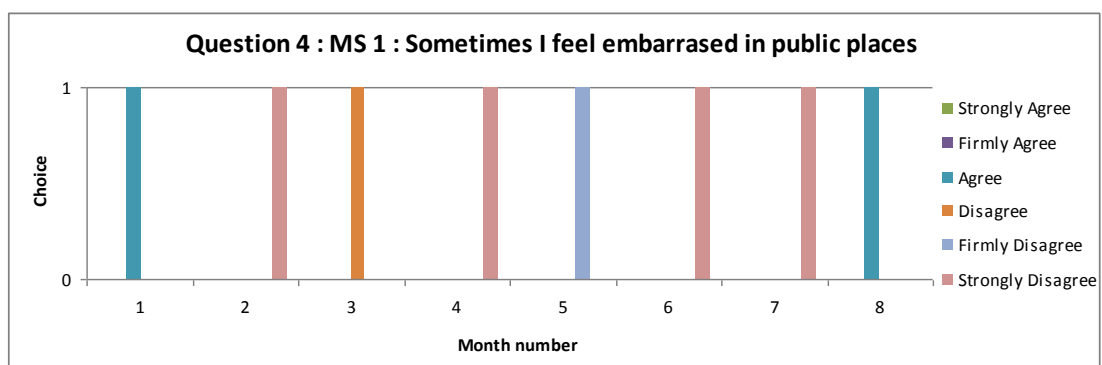
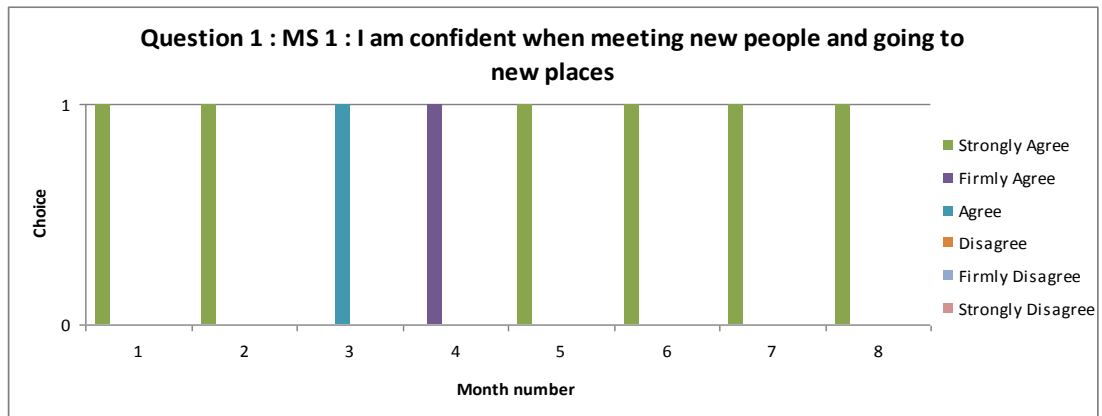
Strongly disagree	Firmly disagree	Disagree	Agree	Firmly agree	Strongly agree
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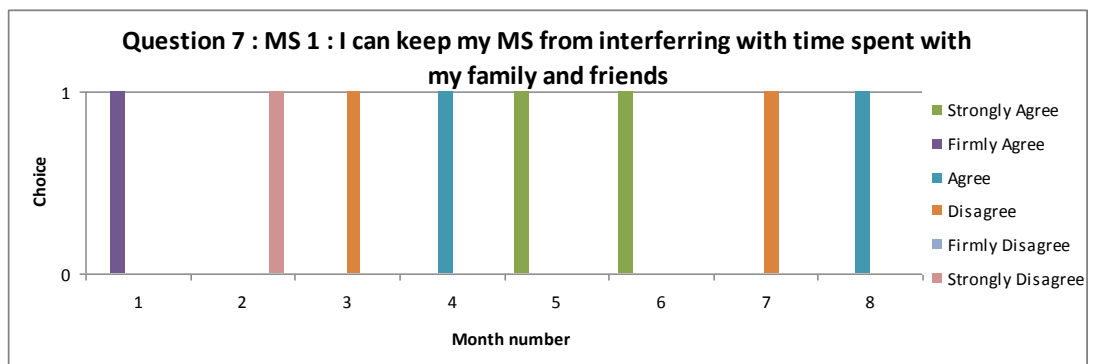
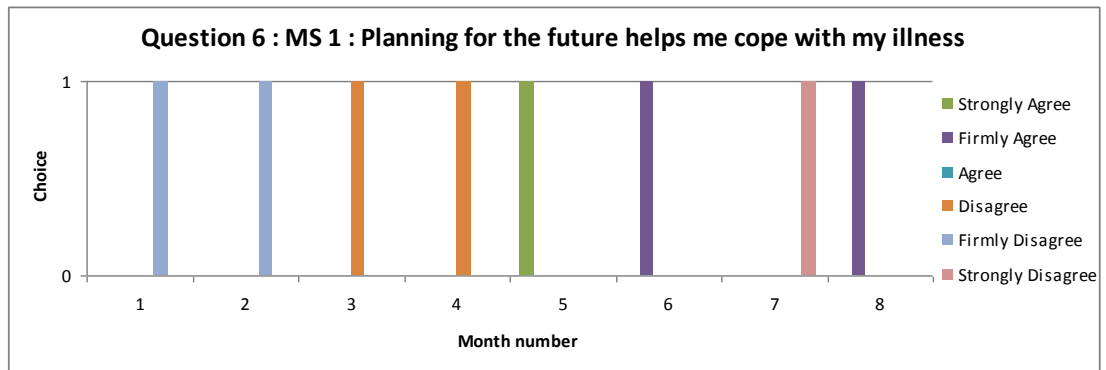
Question 14

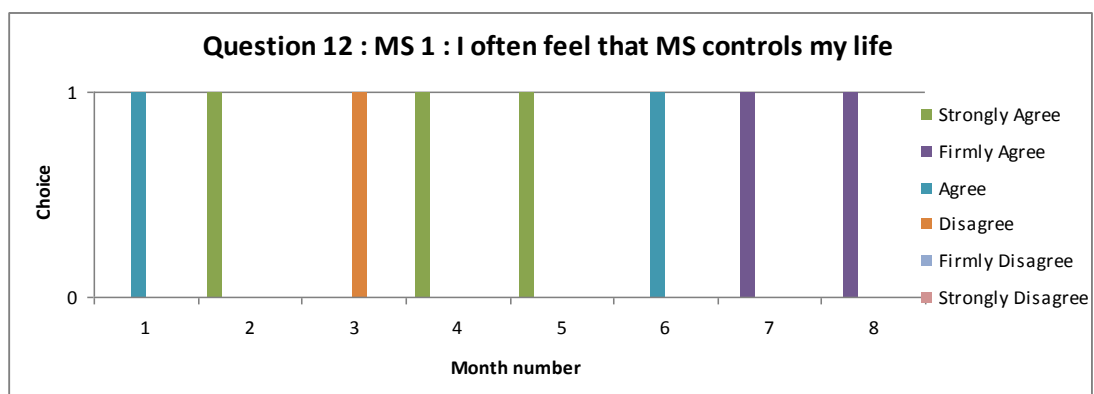
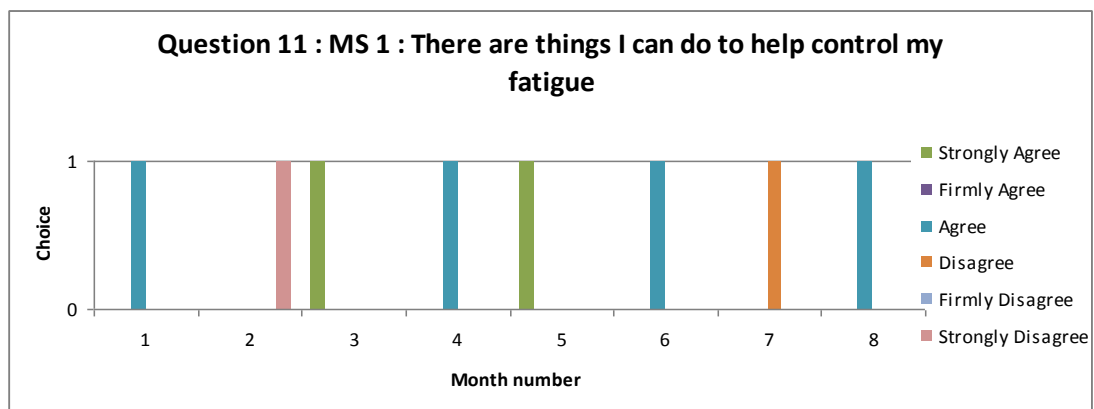
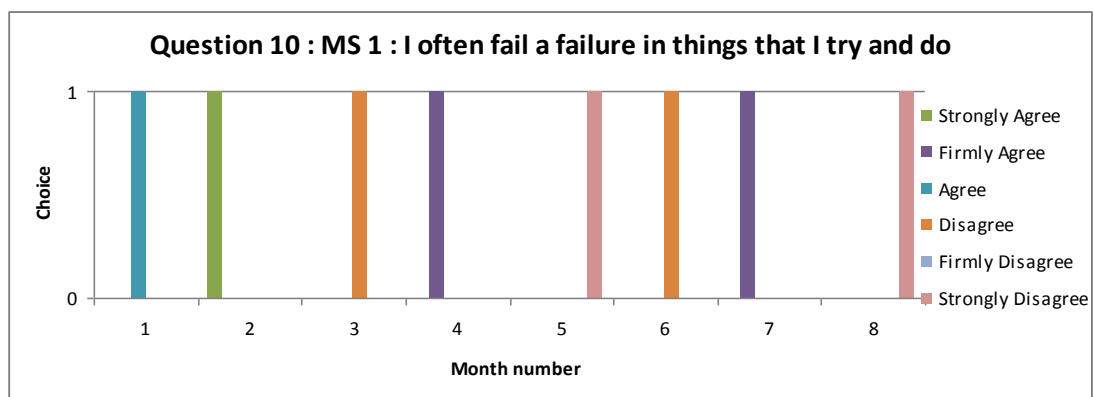
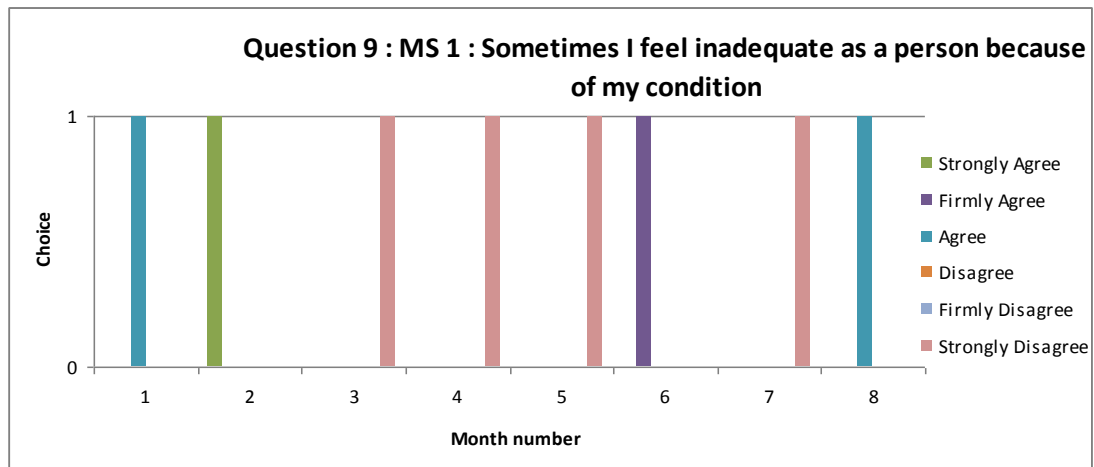
I feel that my social life would be better if I did not have MS.

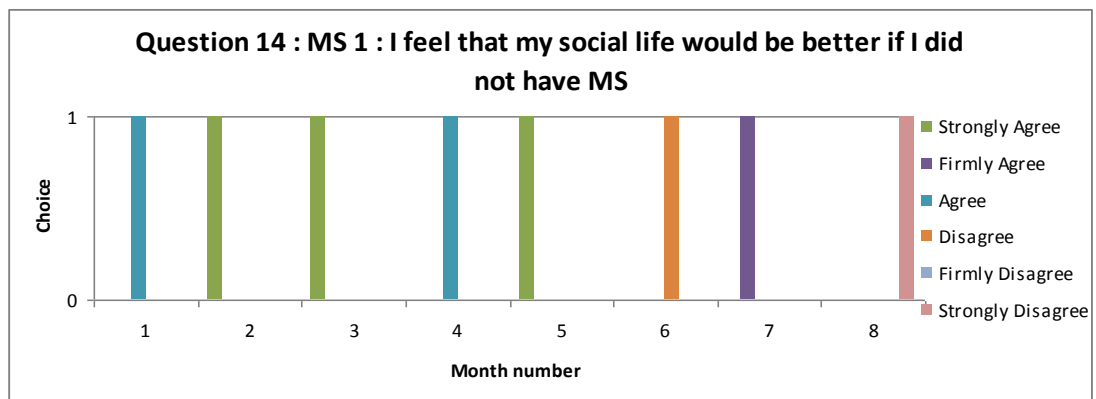
Strongly disagree	Firmly disagree	Disagree	Agree	Firmly agree	Strongly agree
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Rigby, S.A. (2003) **Multiple Sclerosis 9**: 73-81.



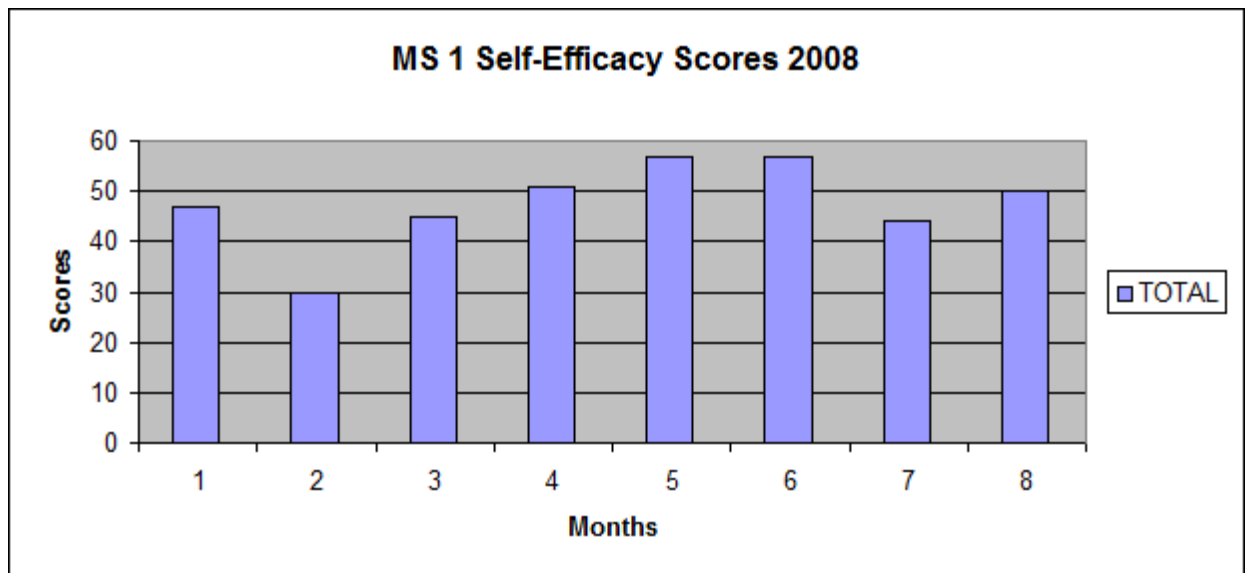






MS 1 2008

Question	Month							
	1	2	3	4	5	6	7	8
1	6	6	5	5	6	6	6	6
2	6	3	3	6	5	4	2	1
3	2	1	3	2	1	1	2	6
4	2	6	4	6	5	6	6	3
5	1	4	3	2	6	3	6	1
6	2	2	3	3	6	5	1	5
7	5	1	3	4	6	6	3	4
8	3	1	1	3	1	5	1	1
9	3	1	6	6	6	2	6	3
10	3	1	3	2	6	4	2	6
11	4	1	6	4	6	4	3	4
12	3	1	3	1	1	3	2	2
13	4	1	1	4	1	4	2	2
14	3	1	1	3	1	4	2	6
TOTAL	47	30	45	51	57	57	44	50



MS 1 MEETING 1	SELF-EFFICACY QUESTIONNAIRE
<p>Early Symptoms</p> <p>Trauma - difficulty with buttons - using the computer at work.</p> <p>Private to speed up diagnosis process.</p> <p>Bad effects after the lumbar puncture.</p> <p>MRI took too long even going private</p> <p>Time off work – waiting for diagnosis was the longest in working life.</p> <p>He said I have a mild form of RRMS.</p> <p>I could have cried my heart out and I did not even know what MS was or what it could do to me – I had my head totally in the sand with ostrich syndrome.</p> <p>I was in control and self-determined.</p> <p>I am confident and able to self-manage.</p> <p>DMT December 2005 to Dec 2007.</p> <p>Unable to self-inject as I do not want to.</p> <p>Youngest person with MS at classes.</p> <p>I have no bad days as such.</p> <p>I continue to work from my diagnosis in 1993 up to January 2007 when I took voluntary redundancy as I knew things were starting to get worse.</p> <p>I enjoyed my job so much I was so determined that I was not going to let MS get in the way of what I really enjoyed.</p>	<p><i>Social Confidence</i> – MS 1 came across as happy, confident and in control, she was satisfied that the things she did during the day made her happy. She stated she had total denial initially and as her condition was getting worse she accepted MS but the denial kept coming back during weaknesses.</p> <p><i>Independence and activity</i> - Proud that she had continued to work for so long and would have liked to continue. She did not feel as independent as she would like but was positive, but did sometimes feel a failure due to MS. She felt in control of her fatigue by resting. She also felt her social life would be better if she could work and did not have MS</p> <p><i>Worries and concerns</i> - She tried to stop MS intruding into her life and family. She had some concerns regarding her condition getting worse and did feel slightly embarrassed in public places. Due to recently feeling worse she had been feeling slightly inadequate due to her MS and felt at times MS did control her and what she could do.</p> <p><i>Personal control</i> – She felt in control and demonstrated self-determination and felt she could do what she wanted and needed to do. She was able to drive and get out and about. She stressed the importance of engaging in self-management and looking after herself through always looking presentable.</p>

MS 1 MEETING 2	SELF-EFFICACY QUESTIONNAIRE
<p>Nobody knows their body like themselves – I knew the DMTs were not working Blood test takes 6+ weeks – antibodies ++ MRI Scan organised Still waiting for treatment and some relief Depressed and tearful I will get better I know I will it has got to. This is only short term – it is not permanent and I will fight it. Life is on hold – big blip at the moment My life is totally in the Consultant's hands and he is at the minute in control of my life and I am not strong enough to take it back I cannot drive my car, go to work, or go shopping, visit my mother or walk my dog all the things that I have always done. I have to vent my frustration + & take it out on my husband and the dog it is on the nearest and dearest who do not deserve it I am feeling lethargic and unwell I feel I am losing control. I feel like a caged animal and I cannot get out – I hate to use a wheelchair or stick I have the commode downstairs to reduce the risk of my falling – but I do not like it and am not happy using it. I will not let them take my independence.</p>	<p>Social Confidence – <i>She still stated that she felt confident but her demure had changed since the last two meetings and her sparkle was not there and she was tearful. She was not feeling happy or satisfied with what she could not do.</i></p> <p>Independence and activity – <i>She liked the idea she did not have to work because she felt she could not due to how she was feeling today. She felt her independence had been taken from her but she was fighting it. Also strongly felt a failure and could not control her fatigue and did not have a social life because she felt so awful.</i></p> <p>Worries and concerns – <i>There were real fears and concerns that her MS was getting worse and she did not even want to be seen outside or by others and felt very inadequate as a person and was feeling that MS was starting to control her life. She was equally determined she was going to fight it and wanted her Consultant to give her new treatment as currently all she was taking was analgesia.</i></p> <p>Personal control – <i>She firmly disagreed that planning for the future helped her cope with her MS and felt her life was in the Consultant's hands. She could not stop MS from interfering with her family and friends due to feeling like a caged animal being unable to drive and therefore felt unable to do what she wanted to do.</i></p>

MS 1 MEETING 3	SELF-EFFICACY QUESTIONNAIRE
<p>MRI Scan eventually came – it is not going to be long now it has taken ages and there was marked deterioration Downhill since August 2007 in 6 months Relief and complete change in outlook and physical appearance – as something is going to happen with treatment Hope for increased mobility – I want this I am becoming more independent/control. There has been a big deterioration in 3 months. I last saw the Consultant at 16-10 hrs 25th March and he noticed. I have had 6 months with no treatment 2 types of treatment one clean / one dirty Monthly infusions with VIP treatment – with 98% reduction in relapses I did not want to hear about side-effects Changed person to who I was 2 years ago New treatment makes me much happier and more positive as something is done I am still using the commode downstairs as there are steps to the bathroom and it is easier to use it in the bedroom next store where I still have my privacy. I am more positive now and am using the special taxi service to get out to my mothers and to go shopping. I have a DVD to watch on my treatment.</p>	<p><i>Social Confidence</i> – There was a marked difference in how she looked and expressed her confidence due to knowing something was going to happen, even though nothing had changed. She was feeling happier but still not satisfied with what she could do and could not drive but was using taxis.</p> <p><i>Independence and activity</i> – She felt she was more independent and in control and really hoped for increased mobility with no wheelchair. She was still feeling a failure but could see the newly proposed treatment might help and she was able to control her fatigue again through pacing herself. Her social life was slightly better but not as good as she wanted it to be.</p> <p><i>Worries and concerns</i> – She was still concerned about her MS and knew if the treatment did not work she may still continue to get worse and she was now not embarrassed to go out. She strongly disagreed about feeling inadequate due to her MS but still felt MS was still a little in control.</p> <p><i>Personal control</i> – At this point she still disagreed that planning was helping her cope and that she could prevent MS from interfering with her time with family and friends or that she could do what she wanted when she wanted. She was more positive and feeling more in control through doing and wanting to do more self-management.</p>

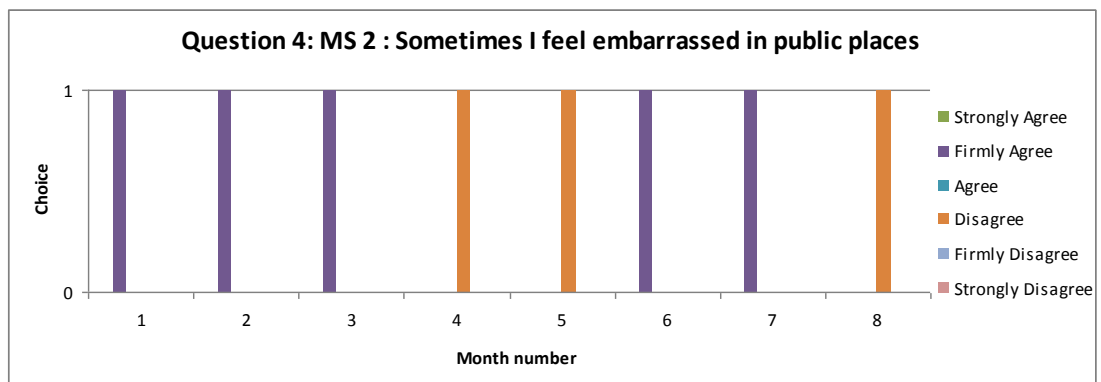
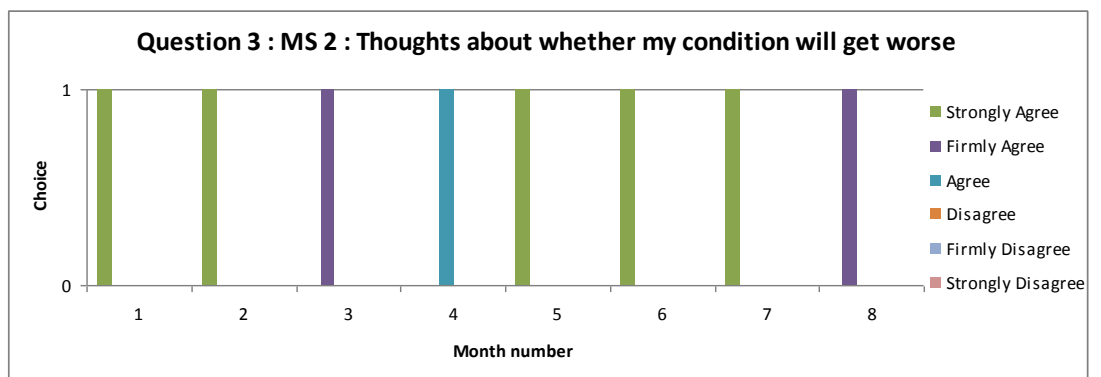
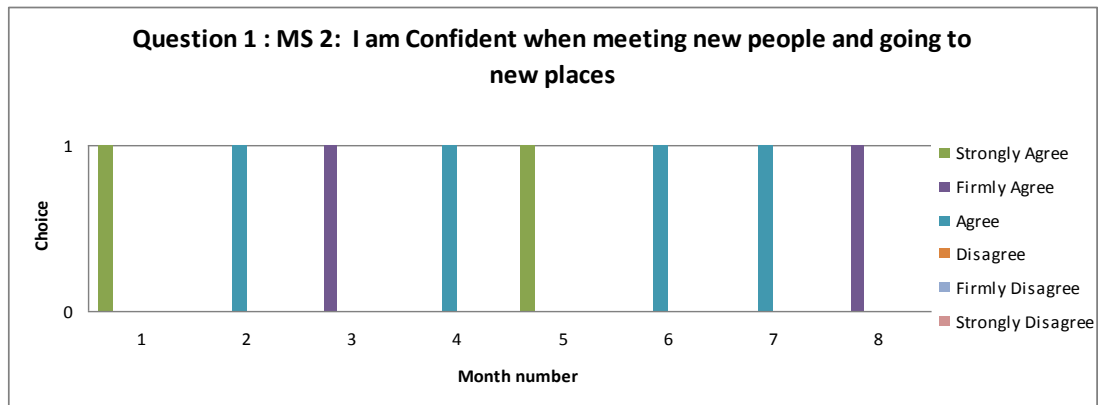
MS 1 MEETING 4	SELF-EFFICACY QUESTIONNAIRE
<p>Second treatment and 2nd and 3rd are the worst in terms of side effects. I drove my car – to be independent and now I feel positive again. The Consultant is listening to me and he is trying another drug treatment. Pity-me Club affected me Buried my head in the sand – always have as I want to block it out. People with MS should look after themselves and self-manage and be in control and always positive. No point on dwelling on things. At the beginning of the year I was cross as I could not adapt to this being the future – I could not stand it like this. Talk about life as a step at a time – I have treatment dates until 2014!! 2 treatments and no difference I was expecting to feel better but not yet. Positive note MS nurses say it is going to get better and think like that. Weather is getting better – positive I am impatient – things not quick enough I hate my current physical limitations. I need to rebuild my confidence.</p>	<p>Social Confidence – <i>Much more confident, in control and feeling happy and satisfied as she was able to drive her car. She had faith in the new treatment and had her second infusion.</i></p> <p>Independence and activity – <i>She was now wishing she was back at work and feeling more independent but still needed some help from her partner. Still feeling a failure in some ways, but in more control of her fatigue and having more of a social life.</i></p> <p>Worries and concerns – <i>Her worries were around the treatment in case it did not work but she felt the Consultant was listening to her. She felt confident in public places even with her physical limitations because she hoped these would be improving soon. She stated she felt very adequate as a person as people were taking notice of her and this helped her feel in control of her life again. She was impatient and wanted a quick result but the hope was bringing the confidence and control.</i></p> <p>Personal control – <i>She was not yet ready to plan for the future with treatment dates up to 2014, but was spending more time with family and friends and doing what she wanted to do. She and her partner had visited the drop in centre and they did not like people with MS going through their life stories with MS and looking for sympathy and moaning about care. It had affected them both and it was this that empowered her to drive her car as she did not want to end up like these people with MS. Her partner was very concerned about her driving as she would not let him go with her but he knew he could not stop her self-control.</i></p>

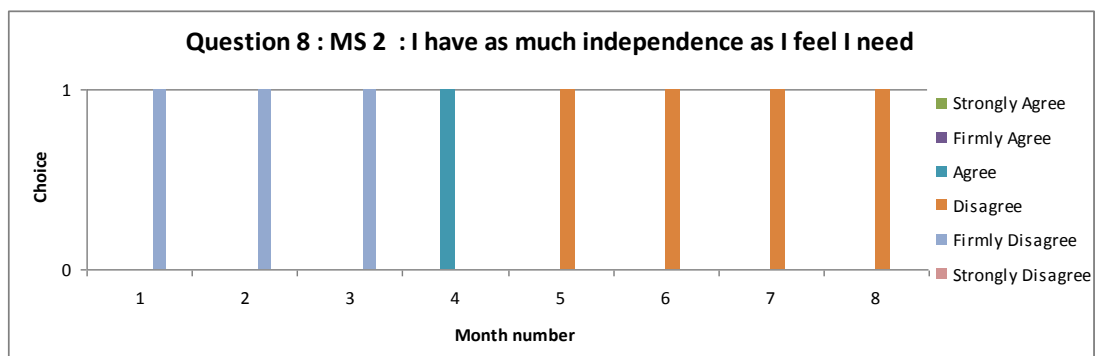
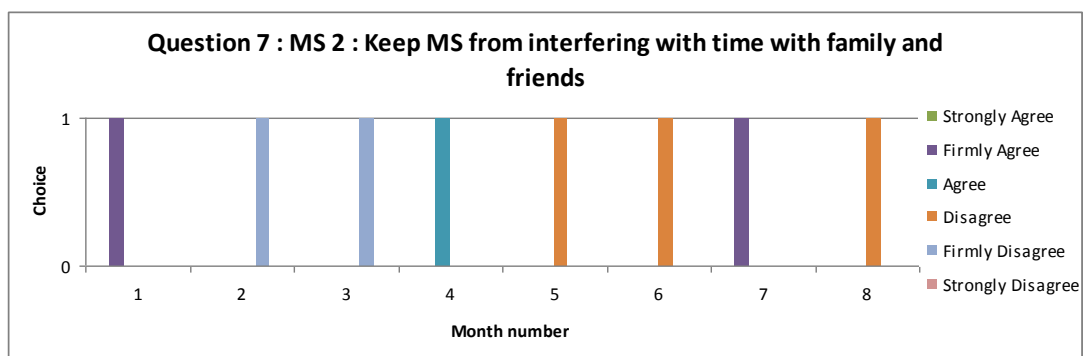
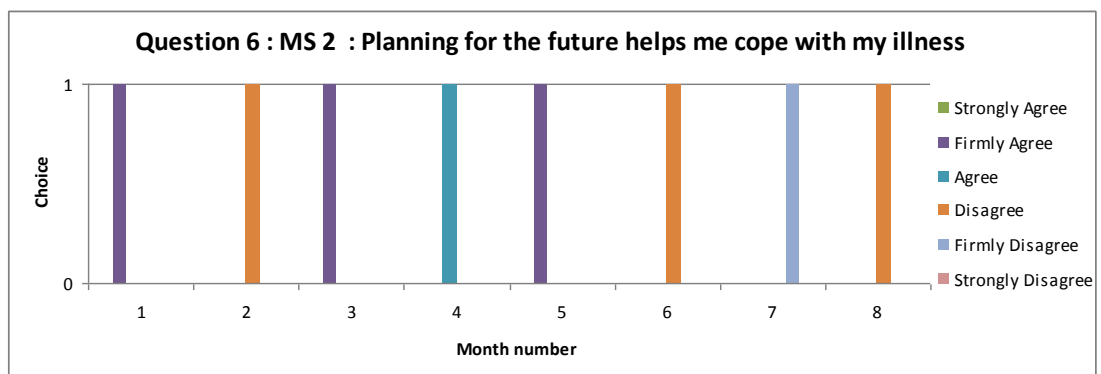
MS 1 MEETING 5	SELF-EFFICACY QUESTIONNAIRE
<p>3 treatments but still no improvements. I do not feel any worse. Walking seems very unsteady / shaky. Finished work in Jan 2007 and then started to accept the diagnosis of MS. I live in hope for new drug to work. I still have ambitions and goals. It is pride – I do not want people to see me in a wheelchair – I need to get rid of my self-consciousness and pride. I have not changed as a person and I still feel I have roles as wife & daughter. Her dog had to be put down – tearful. I drank and smoke too much over Week End as I was so upset about poor Sam. I self-manage and look after myself well at all times and have a good diet. I now feel as positive as ever & am okay My mobility is coming virtually to a standstill at present and I have to use the wheelchair & walker more It is a lot for my husband to accept – but we work together in partnership. My husband worries about me being home alone all day. I am feeling more independent now.</p>	<p>Social Confidence – <i>The confidence was growing with the treatment and she was feeling much happier and more satisfied with what she could do. Her dog had to be put down and she was really upset and grieving for him to the extent of abuse of alcohol and cigarettes over the weekend. Her balance was not good and she had tremors but blamed them on the alcohol.</i></p> <p>Independence and activity – <i>As the weather was good she was pleased to be away from work but still felt she needed more independence. She was positive but upset about the dog and her mobility was not good which was restricting her and she was having to use the “dreaded wheelchair” to get out. She did not feel a failure in the things she tried to do as she had faith that things would get better and her social life was good.</i></p> <p>Worries and concerns – <i>She still had worries that her MS might still get worse as there were no improvements as yet and she did not want people to see her in a wheelchair and even suggested having a plaster cast on her leg to justify use of the chair. She was feeling adequate as a person but still a pull towards MS being in control of her life which she felt was not helped by the grief she felt.</i></p> <p>Personal control – <i>She was planning for her future with her goals and targets including her forthcoming holiday. She was socialising and getting out with friends who knew how upset she was over her dog. She felt her mobility was restricting her but she had support from neighbours and was doing more self-management at this time.</i></p>

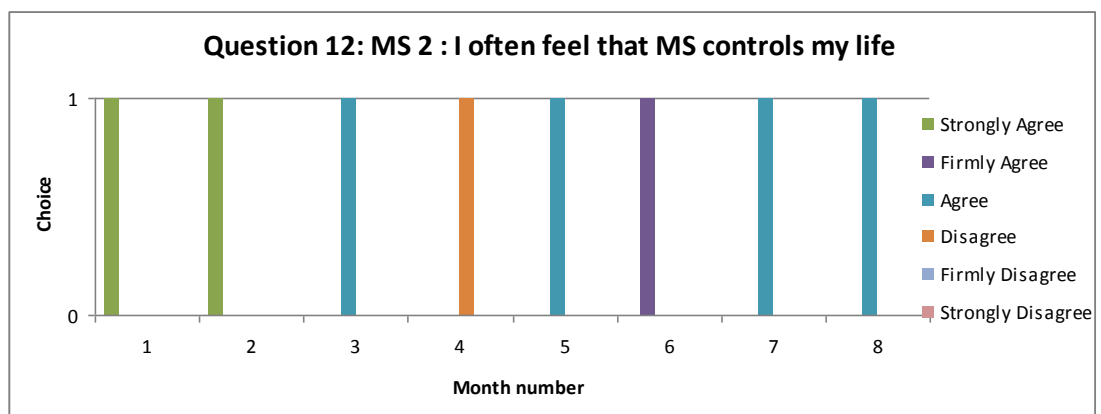
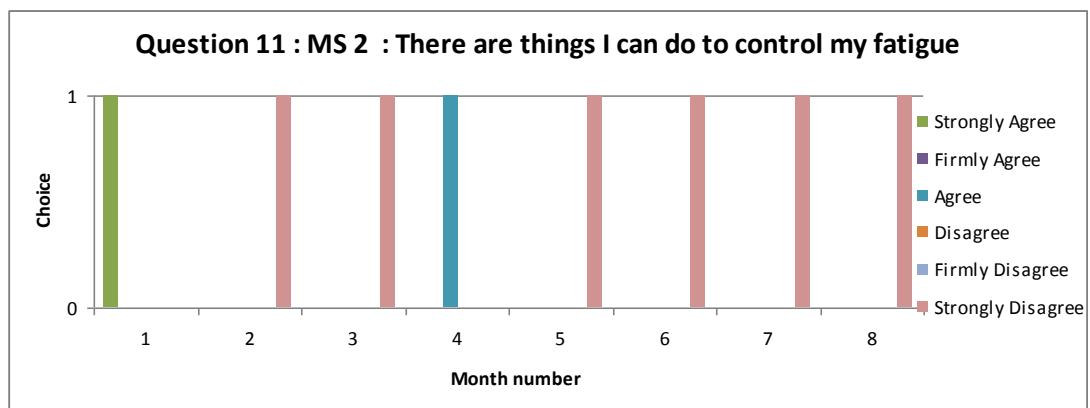
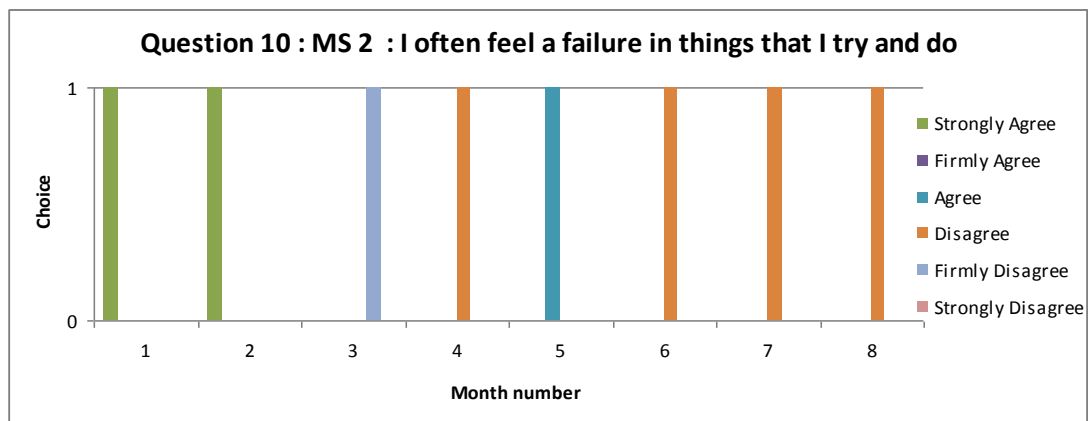
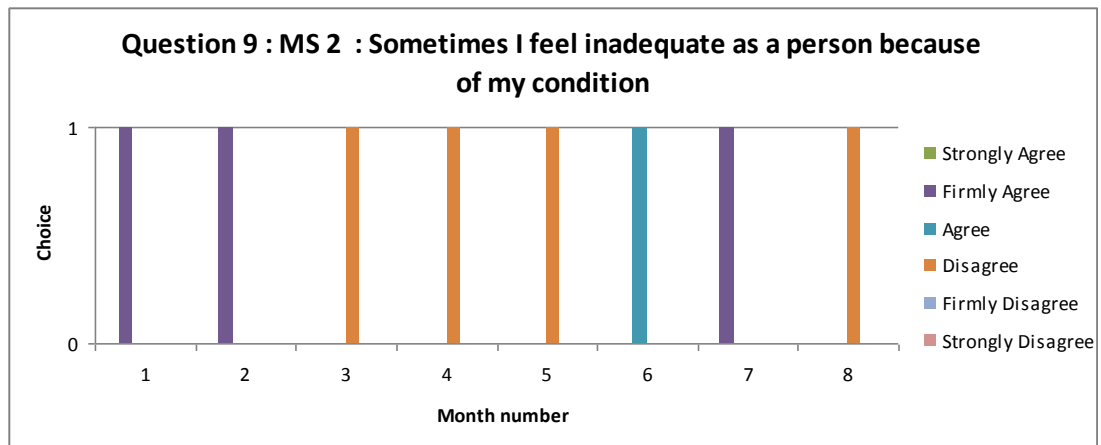
MS 1 MEETING 6	SELF-EFFICACY QUESTIONNAIRE
<p>My tremors are getting worse but the Consultant said he will sort them out. 4th Infusion and my mother thinks my walking is better.</p> <p>I have been driving my car – no problems but I have to steady myself out of the car. I set my mind and manage myself/house. All I want is my mobility to be better. I have to stop letting things get me down. I am still in denial at time with my head in the sand like as ostrich.</p> <p>I am still positive and self-determined. I am determined not to have bad days. I am in control again and independent. Can take 6 months for improvements. I pace myself and I can manage better. The commode is now upstairs and I use it only at night as I can manage the stairs. I am very confident with my Consultant. The death of Sam (the dog) really has affected us all and I am still tearful. I am more positive and I have to be, because of everything that I feel, it is very important to me that I am always positive I see that as part of my control and independence.</p>	<p><i>Social Confidence</i> – The confidence was back on a high with the hope of getting her tremors sorted and she was driving her car again. She was feeling happier and more satisfied with what she could do as her walking was better.</p> <p><i>Independence and activity</i> – Again there was a yearning for work and the company of work friends but she did not feel totally independent as yet but was feeling much more in control. She was feeling useful driven by her self-determination and being positive. Her social life was good again as she felt the MS was not restricting that.</p> <p><i>Worries and concerns</i> – She was still having strong concerns about her condition getting worse but had been told it could take up to 6 months for the treatment to be effective which allowed the denial to creep in again. There were some feelings of inadequacy due to the physical limitations and MS controlling her life at this time but she was determined to get it back.</p> <p><i>Personal control</i> – There was still ongoing planning for the future through pacing herself and being in control. She was convincing herself she was still positive and had to be in order to get more independence back and move away from the uncertainty by managing it better. The belief that the treatment is going to work and the Consultant listening to her and empathising over the loss of her dog was helping to maintain her personal control.</p>

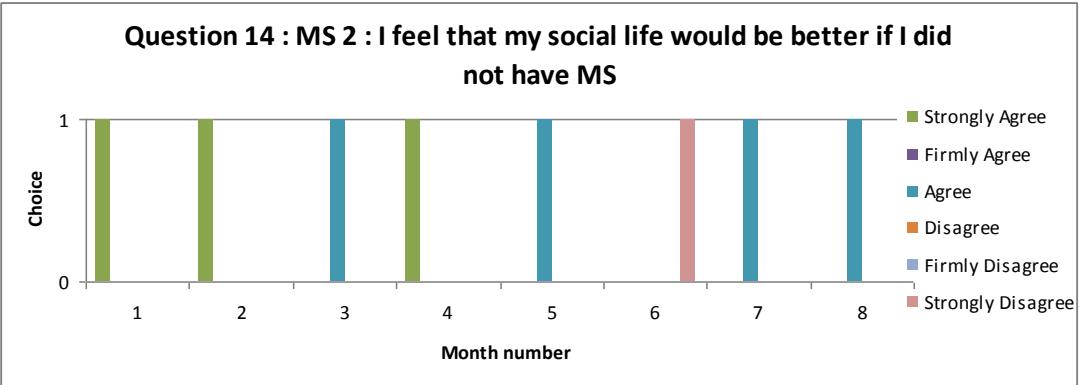
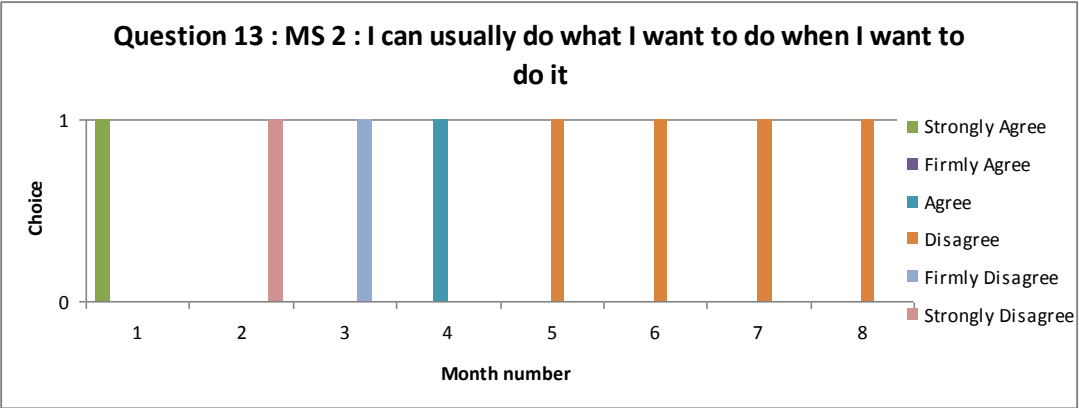
MS 1 MEETING 7	SELF-EFFICACY QUESTIONNAIRE
<p>5th Infusion but still no real changes. No more symptoms but legs are shaking. I have managed to get to the shops. I am able to do the housework. I try to recognise my limitations-mobility. I am a strong independent person. I still have challenges and goals to meet. I do not know how worse I am going to get in years to come. I will always be able to go on holiday hopefully fingers crossed. My denial is still strong at times. I am empowered and will always stop MS from taking over my life. Trying to get a disabled space at home. I do intend to venture out further when my mobility gets better and I am steadier. My mobility is frustration and I hate to let people see that I have to use aids as it makes me feel inadequate- it is my pride. I am not as capable as I was but that will come back with time. My life is living with my husband. My husband is so important to me – he is my number one priority.</p>	<p>Social Confidence – <i>There was still strong confidence and hopes for the future and the treatment working. The physical restrictions was making her feel less happy and satisfied but the drive and determination remained.</i></p> <p>Independence and activity – <i>The independence was there and strong but limited by what she could not do and she wanted more. She was feeling a failure again as her hopes were high for improvements by now. She was stating and accepting the challenges to get it back and be more active as her mobility was everything to her. She was feeling more fatigued and having to pace herself more and feeling her social life would be better if she could do more.</i></p> <p>Worries and concerns – <i>She was worried about her MS and was trying to blank it out with denial but felt empowered to stop MS taking over. She was no longer feeling inadequate as a person except when she had to use the wheelchair which she was very self-conscious about. She still felt MS was in control and it was frustrating but she clearly recognised the importance of her partner and the support her provides her.</i></p> <p>Personal control – <i>The set back of lack of improvements was not helping her planning and goal setting and MS was again seen as interfering with her life and stopping her doing the things she wanted to do. She was living for her holiday and their time away together and that was making her positive.</i></p>

MS 1 MEETING 8	SELF-EFFICACY QUESTIONNAIRE
<p>6th Infusion but still no changes. Tearful and upset about her mother. I have been confident throughout. Still have a degree of ostrich syndrome. My life has been like a roller coaster. The diagnosis does stick in my mind but I did not believe that I had MS – if cannot be me and this is still going on now. I have tunnel vision and denial. From 1993 to 2007 was fantastic – it is only since then that things are worse. I am living on the edge at times with the uncertainty and unpredictability. Mother had a fall and has been admitted to hospital. She has broken her leg. I am still in control but I have had to learn to adjust to MS since 2007. Fatigue has become much worse lately. The waiting for blood results and to start the new treatment really got me down. I coped and worked through relapses until I had the visual problems and head pain. The first words of the Consultant are always in my head to this day. MS Bites back.</p>	<p>Social Confidence – Described her life like a roller coaster as her confidence was up and down but she was upset about her Mother who had a bad fall and was in hospital and this was making her feel useless as she wanted to be there helping her. This was making her unhappy that she could only provide support and they were both needing help from her partner.</p> <p>Independence and activity – Her independence has again been knocked by things outside of her MS but also from the lack of improvements from the treatment. She was reminiscing about how she had coped so well for 14+ years when she was at the top of the ski-slope but now she was rapidly going down the hill. She was craving more independence and again feeling a failure and restricted in what she could do. Her social life would be at a standstill to allow her to visit her mother and sort out who could help with her mother's home and dog.</p> <p>Worries and concerns – She was feeling her condition could only get better and she felt there were very slight improvements which she was recording to share with the professionals. She was able to iron, cook and do some housework and was feeling proud. There was strong worry about her mother and her being inadequate to care for her due to the controls of MS. The uncertainty and unpredictability was getting her down but it was through lack of improvement rather than relapses or the symptoms being any worse.</p> <p>Personal control – She was planning and looking forward feeling in control and that she was adjusting to her MS within the accepted limitations by integrating these into her life and trying to move forward.</p>



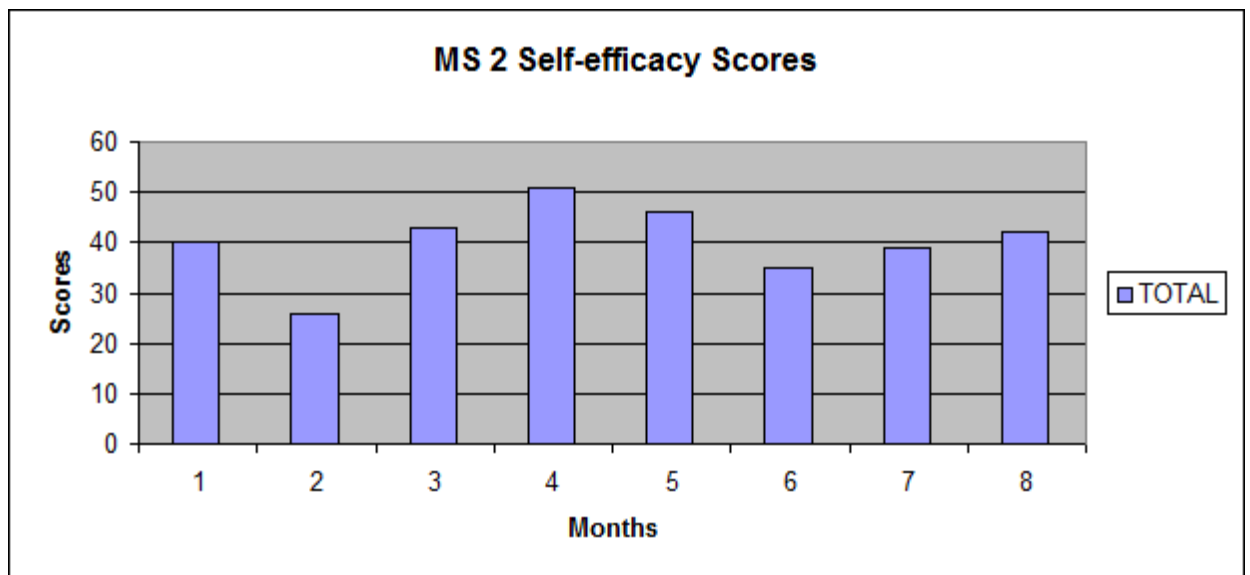






**MS 2
2008**

Question	Month							
	1	2	3	4	5	6	7	8
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3	1	1	2	3	1	1	6	2
4	2	2	2	4	4	2	2	4
5	1	1	3	3	1	1	2	1
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10	1	1	5	4	3	4	4	4
11	6	1	1	4	1	1	1	1
12	1	1	3	4	3	2	3	3
13	6	1	2	4	3	3	3	3
14	1	1	3	1	3	1	3	3
TOTAL	40	26	43	51	46	35	39	42



MS 2 MEETING 1	SELF-EFFICACY QUESTIONNAIRE
<p>I started shaking and felt really dizzy. Was really scared and thought I had a brain tumour or something like that. They thought it was my balance due to ear infections & I was constantly at GPs. MRI for ears showed brain black marks. I found the diagnosis on GPs computer. Once you have the diagnosis there is not much they can do, except they see you every 6 months and write stuff down. You have to laugh to get through it and I can understand why people just give up as it is so scary.</p> <p>I am always tired and my legs are sore but I will manage and do things slowly. It is about being in control and listening to your body at the same time.</p> <p>I just kind of get on with it and block things out and self-manage and am positive. Eventually I was told I had MS.</p> <p>I was quite moved by it & thought about it over the next few weeks – but I knew as I looked it up on the computer.</p> <p>I had optic neuritis which has damaged the nerve at the back of my right eye. I walk with 2 sticks for balance.</p> <p>The unpredictability and uncertainty is bad MS is different for every person.</p>	<p>Social Confidence – <i>She was feeling very confident and enjoyed meeting new people and going to new places. But felt she could be doing more through the day to keep her happy and satisfied.</i></p> <p>Independence and activity – <i>There were strong feeling of not being independent but wanting to work and keep busy. She often felt a failure due to her lack of being able to do much due to her MS with her optic neuritis being really limiting and her mobility. She controlled her fatigue by sleeping each afternoon and pacing herself due to feelings of MS controlling her life at times. She felt her social life could be better without MS but that she had met lots of good friends through MS.</i></p> <p>Worries and concerns – <i>she does worry that her MS will get worse and the impact that might have on her family. Sometimes she feels embarrassed in public places due to her staggering and people thinking she is drunk which sometimes makes her feel inadequate. She is concerned about the uncertainty and unpredictability of her MS but feels she manages this well and laughs to get through most things as she does not want to give up. She feels in control and wants to be more able through listening to her body and managing what is going on.</i></p> <p>Personal control – <i>She believes planning for the future helps her cope and stop MS from interfering with her life. Through being positive and self-managing she feels she can do what she wants to do when she wants to as long as she paces herself. She feels determined and strong willed and controls any help or support she gets.</i></p>

MS 2 MEETING 2	SELF-EFFICACY QUESTIONNAIRE
<p>My walking and dizziness are bad. The fatigue is really draining me and I have more spasms so it is limiting me. I am able to help with the housework. My independence does not allow me to do thing that I want to do, when I want to. I have had problems with my teeth and had to go to the dental hospital. My speech is sometimes funny with slurring of my words I keep forgetting things like names. The things that stop me doing things are my eyes, dizziness and headaches. I walk sometimes like I am drunk. It is not just the MS that stops me self-managing but all the other things I have wrong with me as well. I am confident and strong and always stand up for myself. I have only spoken to the MS Nurses once and have not found them very helpful – they sent me to my GP. I have to go to the toilet a lot during the day and night. I have lots or throat infections and problems with my ears</p>	<p>Social Confidence – <i>Despite feeling unwell with many non-MS issues over the last month she is still feeling confident, strong, happy and satisfied with what she is doing.</i></p> <p>Independence and activity – <i>Her symptoms have been more limiting but she still wants to do more and regain more independence. There have been problems with her fatigue as her routine has changed due to appointments and dental problems. Her walking and spasms have been physically limiting her making her feel more of a failure with thoughts of MS controlling her at the moment.</i></p> <p>Worries and concerns – <i>Due to her feeling unwell she is worried that things might be getting worse especially her eyes and walking which make her feel embarrassed and inadequate but she is determined not to let it get her down. She keeps stressing how positive, self-determined and in control that she is but also feels that MS is still taking some control.</i></p> <p>Personal control – <i>Due to her health her planning has gone astray but she is still planning to lose weight, go on holiday and spend time with family and friends socially. Despite her feeling strong positive feelings she is restricted in what she can do which has been annoying her. Being tired, fatigued and unwell have all had negative effects on her but she states she is moving forward and not letting it get to her.</i></p>

MS 2 MEETING 3	SELF-EFFICACY QUESTIONNAIRE
<p>I went to NGH yesterday and both my eyes are damaged but not my sight. I am determined not to have steroids as they do things to you. Sometimes you cannot self-manage and you need help from other people. My fatigue and tiredness gets to me. Sometimes I wish I had flu and not MS. If you overdo things you are poorly for longer afterwards – MS bites back. The furniture is placed to stop me falling or the risk of accidents. I want to know everything that is going on with my MS and am part of it all the time. I have the ability and confidence to ask questions and know what is going on. I am always in control and involved in the decision-making. My GP does not understand MS. I started swimming classes and exercises to help me lose weight. Writing a diary made me feel depressed. When the professionals are encouraging me to do things I will do things that have benefit to me but will not do things that make me feel worse. All the others at the MS class are older than me.</p>	<p>Social Confidence – <i>The roller coaster is on the rise today with strong confidence and feeling happy and satisfied. She is not happy with the professional input to her care and is determined to self-manage with help from other people.</i></p> <p>Independence and activity – <i>She wants more independence and is trying to balance this without MS making her feel worse making her feel she needs to stop feeling a failure but doing the best she can. Her routine with her fatigue have not been adhered to due to another busy month with appointments and activities. She has been spending time with friends but with everything else going on she feels her social life would be better without MS.</i></p> <p>Worries and concerns – <i>With the damage to both of her eyes she is concerned that her vision and general condition might get worse but is determined to stop it interfering with her family life. She is feeling stronger and more positive and feelings of inadequacy have gone as she prepares to fight and stay positive.</i></p> <p>Personal control – <i>She feels in self-control and with her family is prepared to make the most out of her life and will with their support she will try and do what she wants to do. She felt she needed to say she was still self-managing all of her personal activities and the support is mainly around the house and in taking her out.</i></p>

MS 2 MEETING 4	SELF-EFFICACY QUESTIONNAIRE
<p>I have been having a lot of problems with my eyes which means I have to sit down a lot because of the pain.</p> <p>The spasms in my legs are much worse at night when I am trying to relax.</p> <p>You have to think what you can do now and not want you used to do that is part of the acceptance of MS.</p> <p>I had MS for at least 10 years but was only diagnosed in 2005.</p> <p>My memory is not good and I keep repeating things.</p> <p>Stress and worry make my MS worse.</p> <p>My MS stops me doing the things that I want to do.</p> <p>I never got on with my Mother she thought I was thick and lazy which gave me no confidence. If you are repeatedly told these things you start to accept them.</p> <p>Someone comes from the council to check every so often that we are getting the right help but they never change it.</p> <p>We could be made homeless if the landlord decides to sell this house and he will not do any repairs on it.</p>	<p>Social Confidence – Despite the highlights of the meeting today was a good day and she was feeling very confident, happy with what she was doing and her husband had an interview for a job. He has not worked for a number of years and has been company for her and helped around the house.</p> <p>Independence and activity – She still missed work and had a desire to work if she was able to find a job she could do. Today she felt she had as much independence as she needed and was really positive, self-determined and wanting to do everything. She has increased her exercise classes, swimming and is going to the gym to try and lose weight. Her fatigue is back in control and despite her symptoms she is doing more and feels she is self managing better.</p> <p>Worries and concerns – Her worries were around the cognitive issues and the night spasms in her legs but she was adamant she did not want anymore tablets as she is rattling with the ones she has. She no longer feels embarrassed in public places, feels adequate as a person and feels she is back in control and not the MS.</p> <p>Personal control – She feels well-being and quality of life are improved; she is planning for the future and can do what she wants when she wants to. She shared her feelings as a child who needed psychiatric care as she felt a result of mother and step-family accusing her of things and isolating her. She states she was also bullied at school and was in the family unit with postnatal depression. She was going to make sure her daughter had a better upbringing then she did and this was driving her and making her feel more in control.</p>

MS 2 MEETING 5	SELF-EFFICACY QUESTIONNAIRE
<p>I was poorly all week with cold, dizziness and feeling sick and stuff due to tiredness. My husband is working and I am coping well and being a good little housewife. I have lost 16 pounds and am really proud of myself.</p> <p>The Consultant keeps saying you will feel like this or that but what do they know it does not work like that we are all different. My lifestyle has changed due to fatigue. My eyes are really sore and my vision is blurred and I cannot focus.</p> <p>I am not superwoman and I will not take unnecessary risks. But I am independent and determined and will self-manage.</p> <p>I still get upset about having MS and feel it is not fair on my husband and daughter. I find it much easier to talk to other people with MS than the professionals as they understand it a lot better.</p> <p>I write things down because I forget and I tell the same stories 3-4 times.</p> <p>I pace myself and plan when to do things. I enjoy my exercises, swimming and gym. My life is my family and they help me cope with my MS.</p>	<p>Social Confidence – <i>The confidence, satisfaction and happiness were all very strong again this time. She felt supported and wanted by her family and was positive, determined and happy with her MS friends “the girls”.</i></p> <p>Independence and activity – <i>The yearning to work was still there and she was feeling more independent but still wanted more. At times she did feel a failure which was mainly due to her fatigue and symptoms (not just MS) which sometimes impeded on her social life. Her walking was better and the spasms seemed to be more in control and she was proud at the weight loss.</i></p> <p>Worries and concerns – <i>The main concerns were still around cognitive, visual and effects of MS on her family. She was determined that she was self-managing and doing more around the house ready for when her husband is at work. She is feeling more adequate as a person and still sees MS having some control but she is managing it by working with it.</i></p> <p>Personal control – <i>There is lots of planning going on for the summer holidays and going away which is helping her cope with MS. She is really looking forward to time with her immediate family but there has been friction with her step-family which has been getting her down. The finances are also affecting her as they have very little money and are debating whether or not it is worthwhile her husband actually working or staying home as a full time carer. She states these issues are having an impact on her personal control and her MS.</i></p>

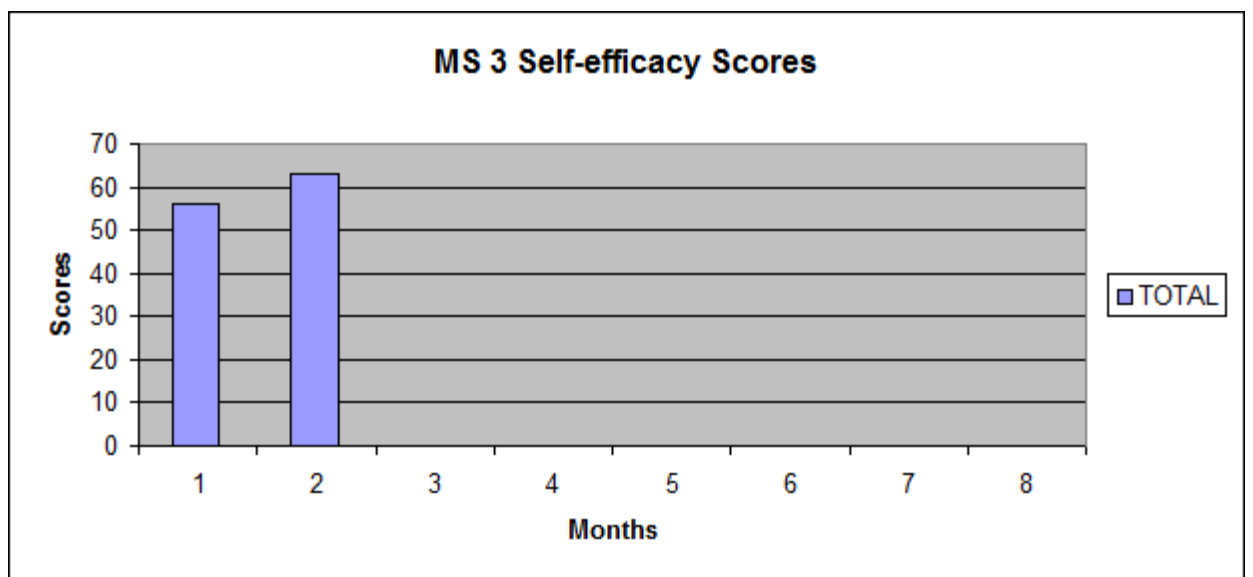
MS 2 MEETING 6	SELF-EFFICACY QUESTIONNAIRE
<p>We had a nice holiday, a good break. My eye problems continue you would think the nerve damage would stop the pain but it does not. It is like a prism. I am very confident and ask the professionals lots of questions. This week I had handrails fitted on the front door to help me get in and out. I try to pace myself to be able to do things but sometimes I forget and overdo it. You cannot fight MS, you cannot stop it but if you lie down and let it take over you will end up in a wheelchair and stuff. I know I am normal now but I have got lots of things wrong with me. My father crashed our new car which was a real shock but thankfully he and my daughter are okay. My husband working is going well but I was worried at first being left on my own for the first time for ages but I am now in control, coping and more independent. I am getting used to my husband being at work and I am coping well on my own. When I feel I need help I have a rest and then I am able to cope with most things alright.</p>	<p>Social Confidence – Fresh back from holiday she was in good form feeling confident, happy and satisfied that things were good and going well. She enjoyed meeting new people in a new place with busy days and lots of activities.</p> <p>Independence and activity – There was still feelings of the need for more independence and going out to work is she was able. She did not feel a failure but was having problems with fatigue with the change in her routine. She also thought her social life would be much better without MS but having said that she slept for a couple of hours each day on holiday and enjoyed socialising and joining in activities in the evening.</p> <p>Worries and concerns – With her husband now working she had some concerns about what would happen if she was unwell and alone. Also how she would cope with the house work as well as her self-management. She was fearful her MS might get worse through doing more and how her father would cope taking her to all of her MS activities instead of her husband. Her father had recently had an accident in their motor-ability car but luckily he and her daughter were both okay but the car was written off. There were feelings of inadequacies as she could not drive and how she would cope. She was still wanting to be more in control of her MS.</p> <p>Personal control – Following the holiday and change in routine she was unable to plan until she saw how she could manage and was waiting to see if she could do all the things she wanted to do. She felt she was in control and was looking forward to showing how she could manage and have the meal ready for the family coming home each day.</p>

MS 2 MEETING 7	SELF-EFFICACY QUESTIONNAIRE
<p>I have had a birthday and I am still 21. My walking has not been good and I have had to use 2 sticks and go slower. My MS is still affecting my eyes and they cannot fix the nerves – sometimes I cannot see at all & it is frightening. I used to be a normal person and never even went to the GP. MS makes me feel much different to what I used to be and things take much longer. Inside I am still me and the way I have always been and I can still have a laugh. I still cannot cope with having to do fewer things when I am not feeling good. I do what I can when I feel up to it and rest when I am not – but I push myself, I have power and control to do jobs I want to do. My cholesterol was very high and my GP has put me on Statins. I am really mad as I have been on a diet for so long. I pretend to be a confident person and I am quite sociable but I think I put on a front because I do not know why but I do. Nobody knows my body like me and I am an expert of my MS in that way because everybody has it different really.</p>	<p>Social Confidence – <i>This was high due to a recent birthday “21 again” and a lunch with “the lasses” to celebrate which helped with her confidence and made her feel happy. The stories were interesting as most people in the pub thought they were drunk not MS sufferers.</i></p> <p>Independence and activity – <i>She was feeling independent especially now she was coping well on her own but still felt she needed more. She feels that things are changed with MS and it is just completely different to what I was pre-MS. Yet the same person repeatedly states you have to plan ahead how you are now – not how you used to be. Despite her weight loss she has recently had her cholesterol checked and it was really high and she is worried about that. Her walking has not been as good and she is using two sticks so feels she is much slower but will do anything to avoid the dreaded wheelchair.</i></p> <p>Worries and concerns – <i>There are concerns about things getting worse and how she would manage on her own during the day which makes her feel inadequate but determined that she can cope. She is balancing between independence and dependency but not wanting to take unnecessary risks. She sees people staring at her and that knocks her confidence a bit. Yet she still feels really positive and wanting to take more control from MS.</i></p> <p>Personal control – <i>She feels she is living day to day to see how this pans out but feels she is in control and the meal is ready for the family most days. It is her body and she is in control and is an expert in her MS.</i></p>

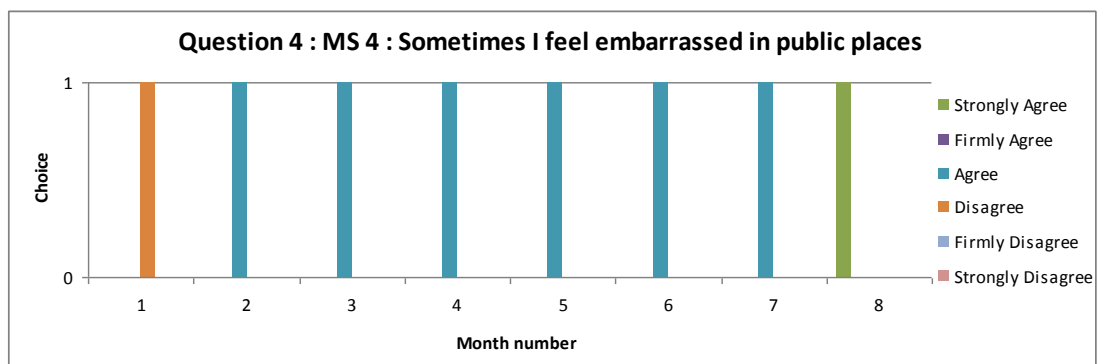
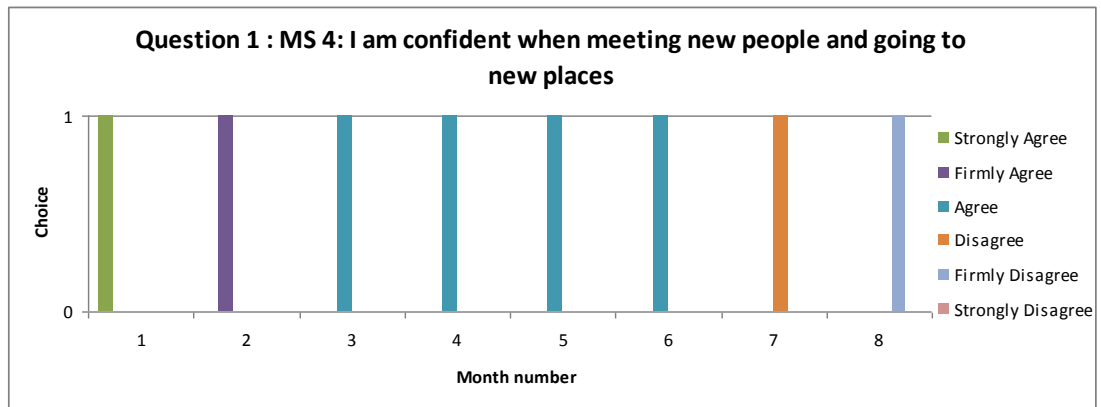
MS 2 MEETING 8	SELF-EFFICACY QUESTIONNAIRE
<p>I have been very unwell and had to go to the RVI but they think it is deterioration rather than a relapse.</p> <p>Everything happened at once my walking, dizziness, spasm and pains, eyes and wobbly legs it was a bumpy time.</p> <p>I am gutted at myself because I am sitting here getting fatter and I had such a good routine going to try and stay fit & healthy. My fatigue is slowing me down and it drains me.</p> <p>I hate not being able to do stuff in the house because men never tidy up properly and I am not being cheeky.</p> <p>I do have a vision for the future but I try not to think about it as it is uncertain.</p> <p>I can still self-manage and do everything for myself in getting ready & everything.</p> <p>I really enjoy meeting other people with MS and have met some great people that I would not have met otherwise. They keep saying that I am the youngest.</p> <p>I never want the MS to get too severe and I never want to end up in a wheelchair.</p> <p>I had lost over 2 stone but I have put on over half a stone and it is annoying because I cannot do my exercises now.</p>	<p>Social Confidence – <i>The confidence remains high but the fears of being alone at times during the day are causing her some concern. She has had a relapse/deterioration which is the first one for a very long time and has had to have steroids which has affected her in case it happens again.</i></p> <p>Independence and activity – <i>There is still a feeling of needing more independence especially after the deterioration setback which has left her feeling more inadequate and a failure. Her fatigue has also been causing increasing problems and she is having to slow down which causes concerns about her weight and not being able to do more in the house. Her social life is also not happening at the moment but that does not seem to be problematic to her.</i></p> <p>Worries and concerns – <i>The worries are high on things getting worse on the bumpy ride she has had recently making her feel more inadequate and less in control. Her concerns were letting her family down and she even stated that she wanted to go into a nursing home if things became any worse. She is determined to get back into her routine and stay in control and get more of her costiveness back to show she can do it.</i></p> <p>Personal control – <i>She praises herself on her self-management and doing everything herself through sheer self-determination. The personal control drives her to take care of herself and to avoid the wheelchair at all costs. Her vision for the future is difficult due to the uncertainty and unpredictability but she feels the steer to demonstrate she can cope and plan ahead as she states no matter what she is not giving up her summer holidays.</i></p>

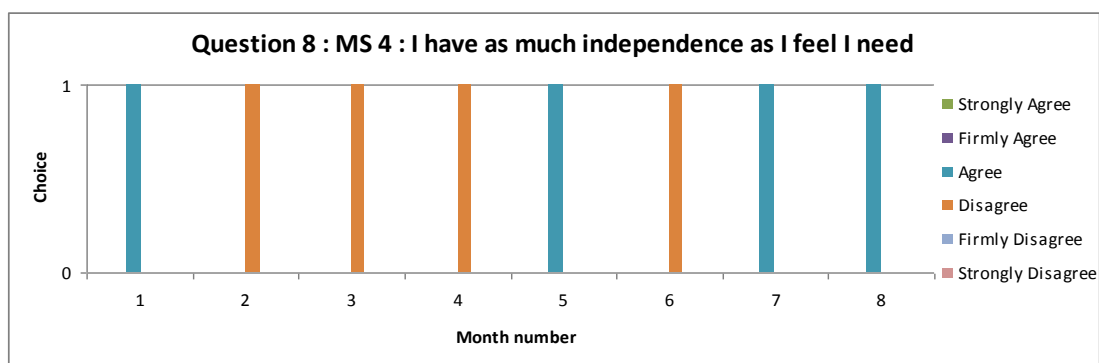
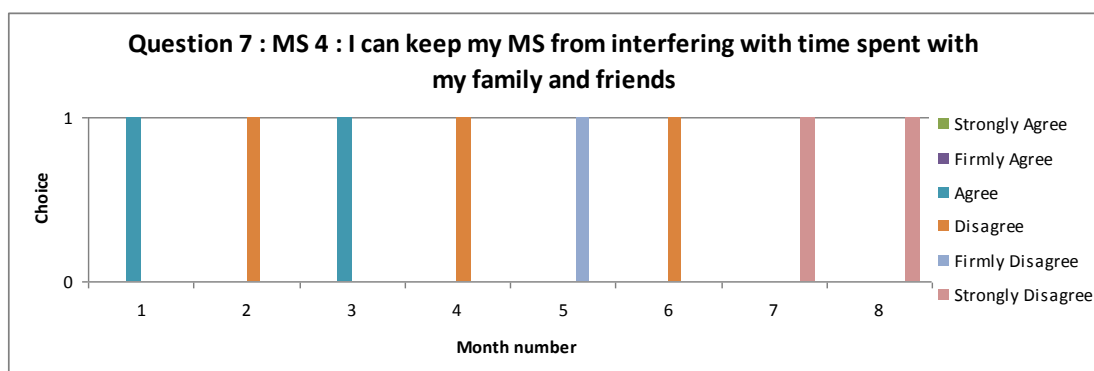
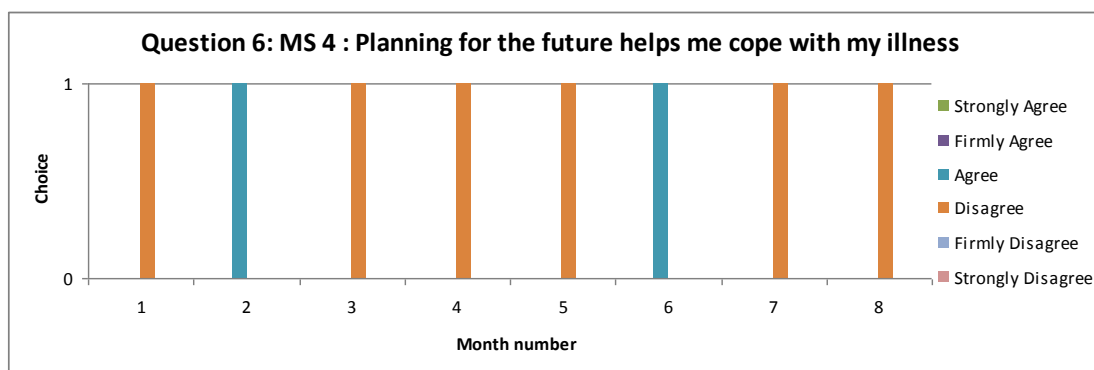
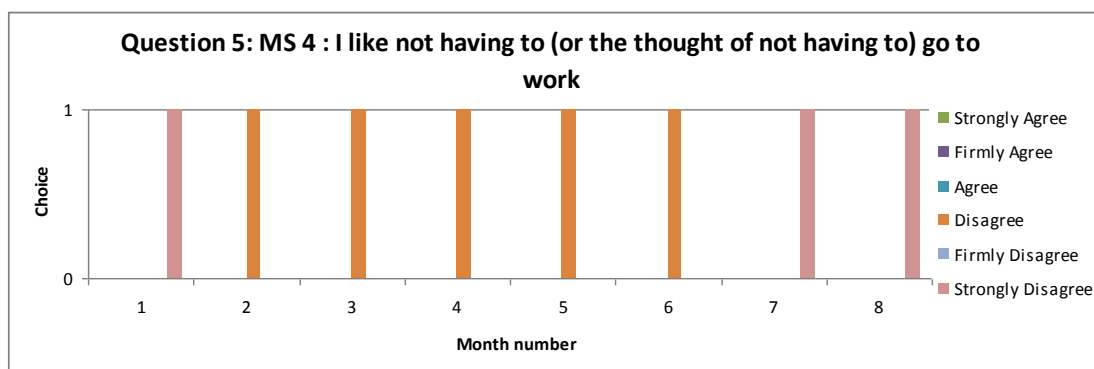
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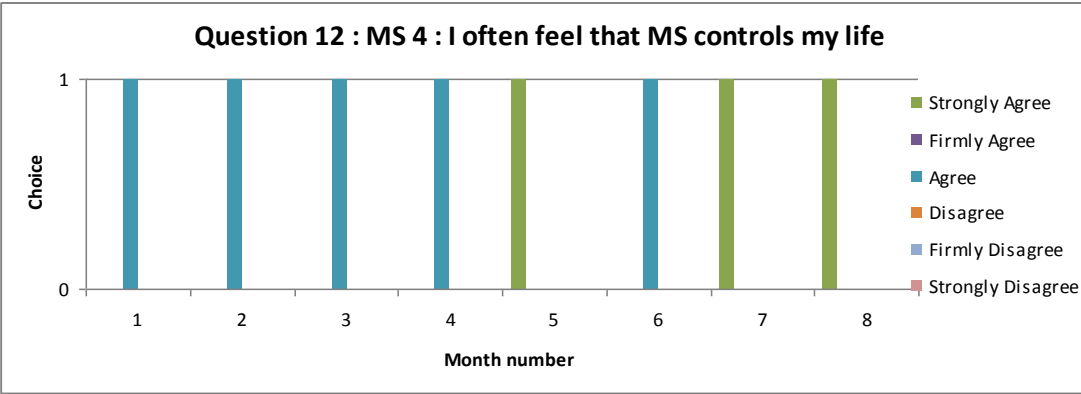
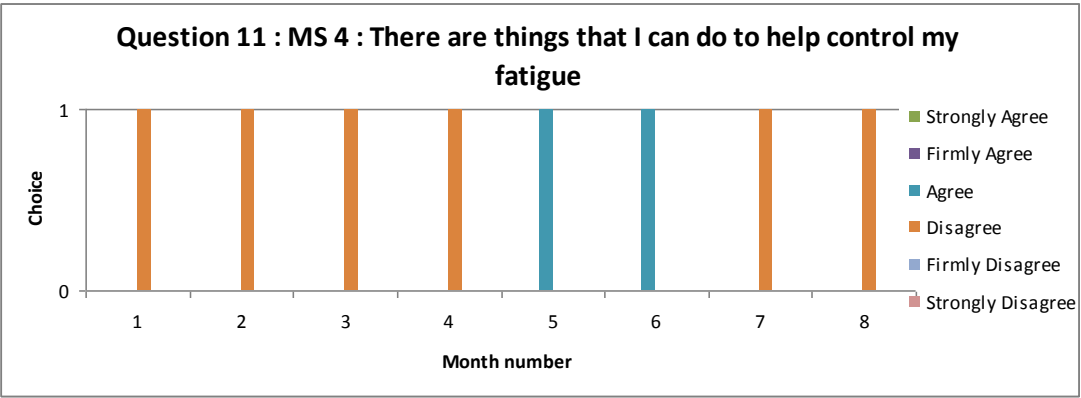
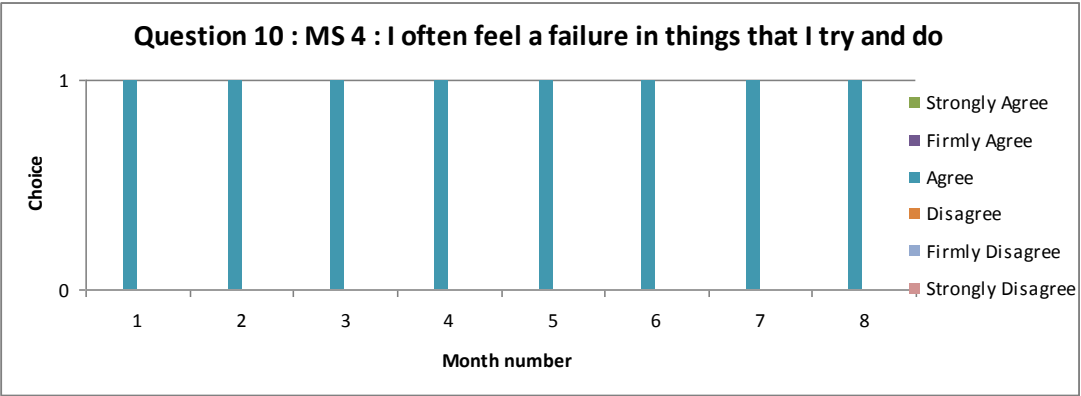
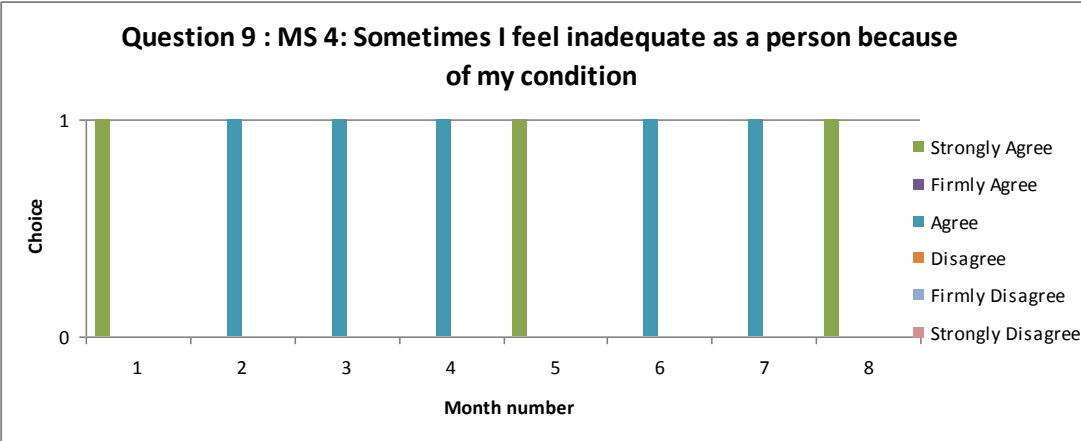
Question	Month							
	1	2	3	4	5	6	7	8
1	4	6						
2	4	5						
3	2	2						
4	6	6						
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7	4	4						
8	5	4						
9	4	5						
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12	4	4						
13	4	6						
14	4	5						
TOTAL	56	63	0	0	0	0	0	0

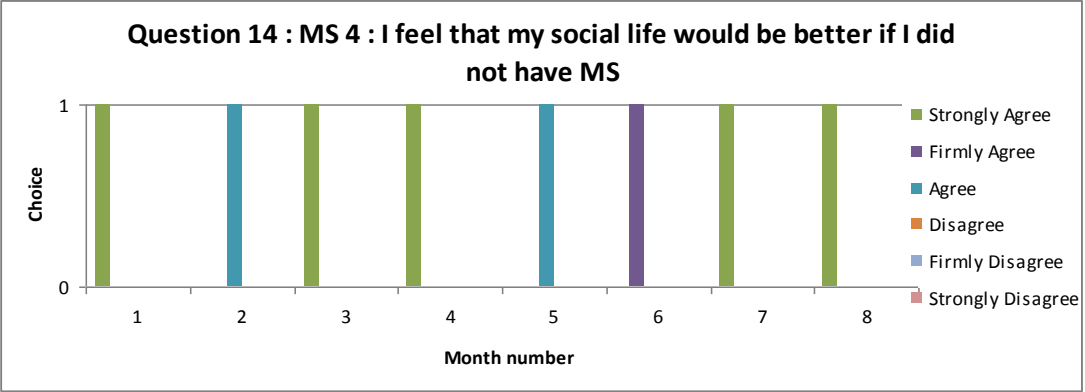
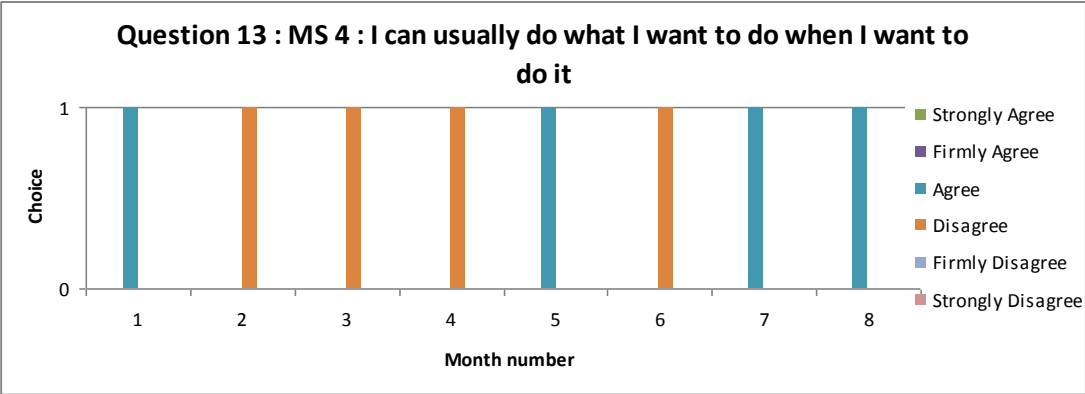


MS 3 MEETING 1	MS 3 MEETING 2	SELF-EFFICACY QUESTIONNAIRES
<p>I woke up with symptoms and thought I had been lying awkwardly. It only took from July to September 2006 to reach 85% certainty of diagnosis of RRMS. I felt relieved because MS was not life threatening and you do not die from it. I thought I might have cancer or a brain tumour because it was on the right side. My work have been very supportive. I know if I have any problems I can ring the professionals at any time.</p> <p>The Consultant said that I would probably end up in a wheelchair in 20-25 years. The drugs have helped my tiredness, fatigue and reduced the relapses. I am trying to balance out everything. I have had a change in my lifestyle and my job and am struggling with my weight. I have insomnia and other problems every time I have steroids.</p> <p>I am in control and feel very positive. I have a good partnership with my GP and we are working together discovering MS. It is about sharing and helping each other come to terms with symptoms & coping. I know where I am going with things and where to get support when I need it.</p>	<p>I had a bad relapse in March and it has been the worst to date it was awful. Because it was a BH I had oral steroids. I could not drive because of optic neuritis. Now I am almost back to where I was but have a few niggles in my leg.</p> <p>I am still able to self-manage and do stuff and get out and about but I did use a stick for a couple of weeks for my balance. I am having problems saying things and remembering them and I have to write things down. It is really frustrating. Work have been great and I really enjoy it and the people I work with.</p> <p>I have my independence back almost to a 100% and feel a lot better and in control. I had a letter from the physio saying I was on the waiting list but I had already been off for 2 weeks so I rang up and got an appointment in a couple of day.</p> <p>I rang the GP and asked for a walking assessment and they sent the OT out. I now have good contacts and if I do have problems I can jump straight in and they can come out and give me that help. My family are very supportive and we all help each other.</p>	<p><i>Social Confidence</i> – He was more recently diagnosed and moved quickly through the system with confidence, control and articulation. Unfortunately due to him being unwell we were only able to do two interviews.</p> <p><i>Independence and activity</i> – He was very independent and able to get through the system to make sure he quickly got the help he needed. Also been involved in the MSS and had a social network/peer support. He was still working although his hours and position were altered to cope with MS. He felt independent, did not think he was a failure, controlled his fatigue and had a good social life.</p> <p><i>Worries and concerns</i> – He was concerned about his MS and relapses every bank holiday. He stated he felt adequate and in control of his MS.</p> <p><i>Personal control</i> – He planned for the future to help him cope, kept his MS from interfering with family and stated he could do what he wanted to do around his MS.</p>



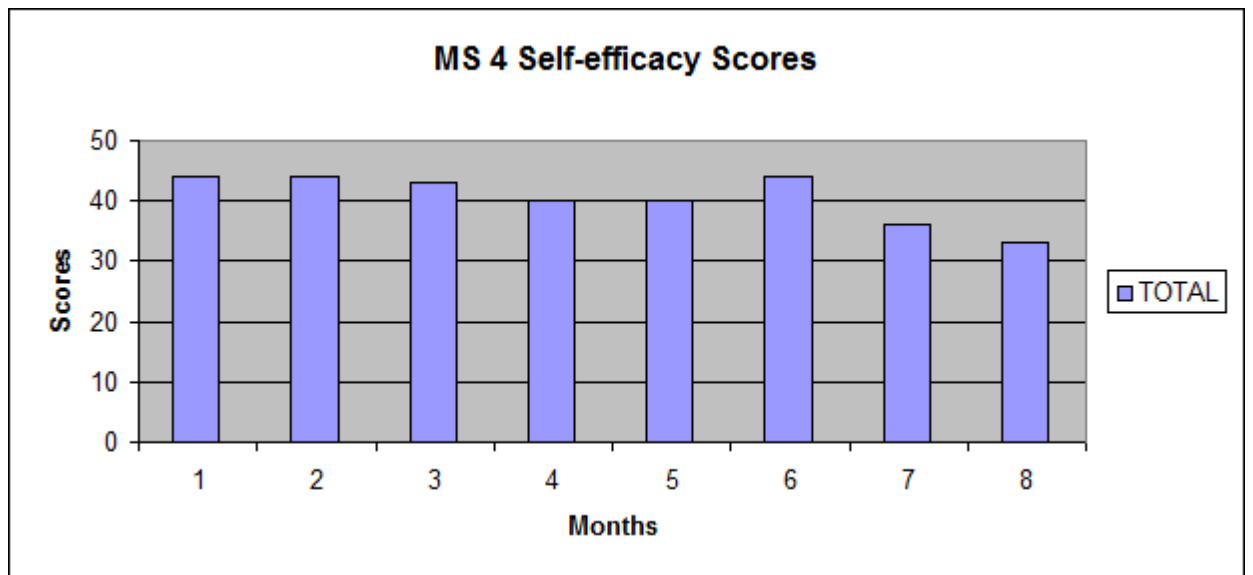






**MS 4
2008**

	Month							
Question	1	2	3	4	5	6	7	8
1	6	5	4	4	4	4	3	5
2	6	4	4	4	4	4	4	4
3	1	1	3	1	1	2	2	1
4	4	3	3	3	3	3	3	1
5	1	3	3	3	3	3	1	1
6	3	4	3	3	3	4	3	3
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8	4	3	3	3	4	3	4	4
9	1	3	3	3	1	3	3	1
10	3	3	3	3	3	3	3	3
11	3	3	3	3	4	4	3	3
12	3	3	3	3	1	3	1	1
13	4	3	3	3	4	3	4	4
14	1	3	1	1	3	2	1	1
TOTAL	44	44	43	40	40	44	36	33



MS 4 MEETING 1	SELF-EFFICACY QUESTIONNAIRE
<p>I was dropping things, falling down, bumping into things & feeling quite silly. Some months would pass and I would be okay, then for a few weeks it would start again & the GP sent me to the hospital. I went private because there was a massive waiting list for a neurologist. I had optic neuritis and was admitted for steroids and investigations.</p> <p>I do feel empowered and able to ask questions and probe for information. Most of the time I am in control and go places depending on the toilet facilities. My walking is not so good now and I can only walk short distances with a stick.</p> <p>I am determined to be in control of my own self-management. I have always had positive thoughts & self-determination. I am not going to let MS rule my life and my family and I am just determined that I am going to cope as long as I am able to do so. I have to think about my family and how they are coping with my illness and they are always every supportive.</p> <p>I do make an effort & ensure I am always presentable and want my family to see me as this all of the time.</p> <p>My husband and I are very close.</p>	<p>Social Confidence – <i>This person was the most determined, confident, positive and in self-control throughout she stated her 20 years with MS. She had great confidence in meeting and supporting newly diagnosed people with MS and kept herself fully occupied and feeling happy and satisfied with her days.</i></p> <p>Independence and activity – <i>She had really enjoyed working and would have continued if she could but had risk and safety concerns. She felt she had enough independence as she needed, but did feel a failure at times when she was not able to do things. She rested when she was fatigued but did not feel she could control it and felt she could have a better social life if she did not have MS. Her activities were governed by knowing about the toilet facilities which were planned en route. She still drives her car, walks with a stick and has a great dread of wheelchairs.</i></p> <p>Worries and concerns – <i>She does worry her MS may get worse but will not let it rule her life and does not feel embarrassed in public places due to her self-confidence. There are times when she feels inadequate due to MS when she cannot play with the grandchildren and go hill walking. She feels MS restricts her life in some ways due to the uncertainty and unpredictability. She is always very presentable and makes an effort to look good but worries her family will see her as being unwell.</i></p> <p>Personal control – <i>She does plan well bakes for people, does church work but does not find MS future planning helps her cope. She keeps MS from interfering with her family and friends and can usually does what she wants to do when she wants to do it.</i></p>

MS 4 MEETING 2	SELF-EFFICACY QUESTIONNAIRE
<p>I fell over in the road when shopping. I felt such a fool and just wanted to run away with embarrassment. I am having problems with my big toe and I can only wear sandals. I got such a shock and it makes you feel awful and silly. I am going to get an appointment with a Chiropodist. My problems with urgency & frequency are still really bad and controlling. I have been having DMTs for 16 years with very few relapses.</p> <p>I am still active, buzzing about, do all my own self-management and still driving. MS is not going to control me but I am going to control it.</p> <p>I manage to do most things and keep busy and will not let things knock me back.</p> <p>I have always been a lively person wanting to do all kinds of things and whatever which make me more resentful because I think why did this have to happen to me. I cried every day at first and I was so upset. My family were all young and I tried to get on with our lives and forget that I had MS and most of the time I could do this.</p>	<p>Social Confidence – <i>Her social confidence was not as high today but may be due to an embarrassing fall she had due to problems with her big toe. She still felt confident and happy but a bit shocked as she fell this morning.</i></p> <p>Independence and activity – <i>She felt in need of more independence this time and still agreed that she felt a failure at times due to MS limitations. She disagreed that things did not help her fatigue but was too active to consider sleeping or resting through the day. She still felt her social life could be better despite being actively involved in the MSS and going out socially with friends a couple of times a week.</i></p> <p>Worries and concerns – <i>She was worried her condition could get worse and having the fall was causing her concern although it did not seem to be MS related and she was embarrassed by it. Sometimes she still felt inadequate as she was having problems getting her toe seen too. Despite stating she is not going to let MS control her and that she is in control she still agrees MS controls her life.</i></p> <p>Personal control – <i>She is feeling more in control stating she has stopped MS from interfering with time with her family and friends. Planning for the future helps her cope with MS but this time she feels her limitations are stopping her doing what she wants to do as her toe is causing pain, tripping and falling and making her even more tired.</i></p>

MS 4 MEETING 3	SELF-EFFICACY QUESTIONNAIRE
<p>We went to the MS Life Conference in Manchester. It was great to see loads of people with MS there but I had heard all the talks and that before.</p> <p>My big toe was really annoying me and I eventually got to see a chiropodist and he cut away at the toe. It was much better with no pain for 2-3 days but now it is worse than ever. I cannot get to see him for 7 weeks & it is affecting my walking. I was concerned that I was putting on weight and my GP told me I should go swimming but I like to go with someone so will have to wait until one of the family are available to come with me.</p> <p>My MS disempowers me sometimes when I cannot do what I want to do when I want to do it. Once you have MS you cannot get rid of it and there is nothing they can do which is a bit sad, it cannot be cured and it is never going to go away.</p> <p>I use my knowledge to help newly diagnosed people as I feel sorry for them but now of course there are the MS nurses who were not around in my time. Professionals see me as an expert in my own MS and value my opinions.</p>	<p>Social Confidence – <i>This time she completed all questions in a straight line of agree or disagree with one exception which was strongly agree that her social life would be better if she did not have MS. Which is interesting as her husband is very sociable and at the MSS conference she felt she was left with her friends while he went to sessions and spoke to people. She is proud of him being involved with the MSS but is also very possessive and wants him to be with her at all times.</i></p> <p>Independence and activity – <i>There were also feelings of needing more independence which could be due to the restrictions which her toe was causing due to pain and discomfort which was also limiting her mobility, independence and disempowered her as she felt she wanted an earlier appointment.</i></p> <p>Worries and concerns – <i>The main worries was the big toe and the fear that it could have on her mobility with MS and the fact she felt she was put on weight and could not go swimming. She was feeling inadequate because of the restrictions and that MS and her big toe were controlling her life. She was concerned and it was starting to get her down as she did not feel comfortable.</i></p> <p>Personal control – <i>Surprisingly she was not in control and feared the receptionists at the GPs surgery who did not see her as a priority. She did however manage to keep this from her family and friends but it was stopping her doing the things she wanted to and normally was able to do.</i></p>

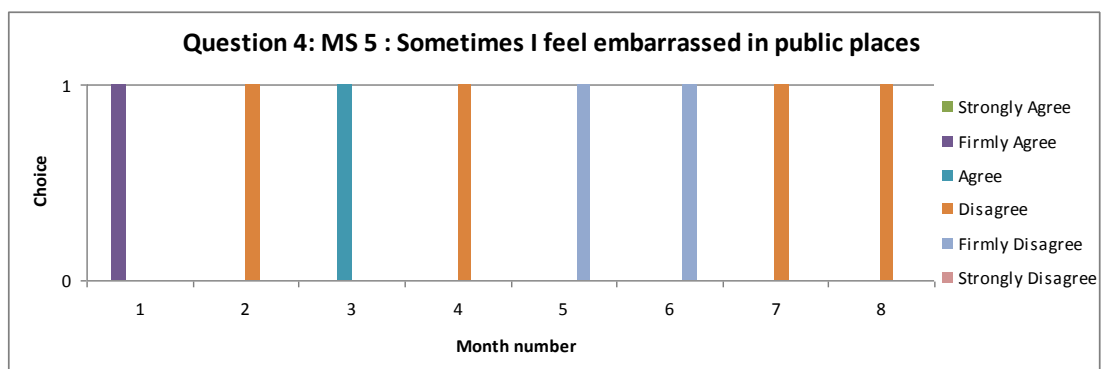
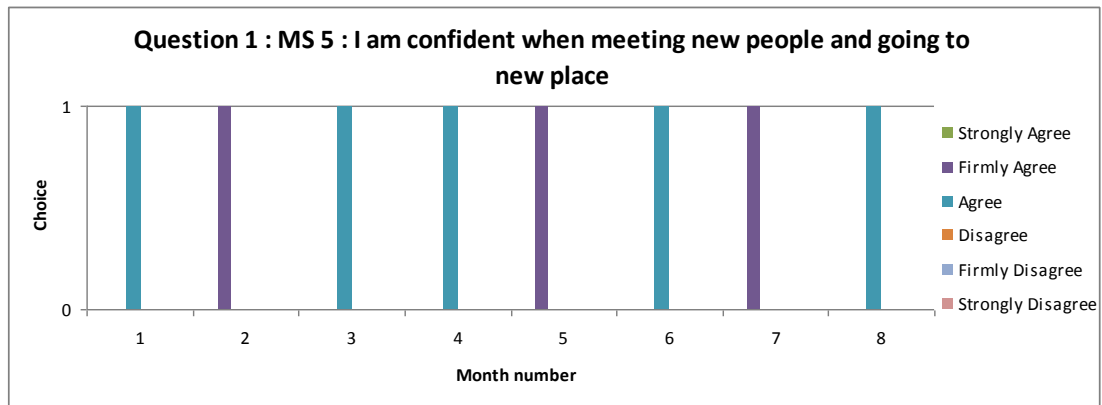
MS 4 MEETING 4	SELF-EFFICACY QUESTIONNAIRE
<p>I am finding I am not walking as far when I go out and I am tripping up due to my toe. The receptionist will not let me have an earlier appointment to see the chiropodist and my husband told me to go and see my GP as the pain is so bad. It is affecting my walking and balance.</p> <p>They ask if you are a diabetic but I feel MS should also have priority because of the importance of mobility.</p> <p>My waterworks are much the same with frequency and urgency.</p> <p>I am independent and able to do everything myself and manage my MS. I can still drive my car and have my independence that way.</p> <p>I always try to be positives & in control. Many of the people who were diagnosed at the same time as me who went to the physio classes are now really disabled. Also many of them had their partners walk out on them so I am much better off in both of these aspects.</p> <p>I would hate to have to use a wheelchair or a scooter I think they take away your control and independence.</p>	<p>Social Confidence – <i>She was feeling more confident and happier with things but there were still ongoing problems in getting her toe sorted which was affecting her.</i></p> <p>Independence and activity – <i>She was still seeking more independence and wanted to stand up more to the GPs receptionists and get things sorted out but feels they are not listening to her. She feels she is failing in this and it is getting her down. This time she strongly agrees her social life would be better without MS which related to family and change issues in the home.</i></p> <p>Worries and concerns – <i>There were concerns expressed around of number of non-MS related illnesses and sharing of events. The toe and mobility were getting her down and she had strong feelings her MS would get worse with talks about her peer group and how their MS was much worse than hers. With her affected walking she was feeling embarrassed in public place but was still managing to drive but was not going out as much making her feel more inadequate. She did keep herself busy in the home but was feeling that her MS was more in control.</i></p> <p>Personal control – <i>Her personal control was also affected by these frustrations – she felt she could not plan to things were sorted, MS was interfering with her time with the family and she could not always do what she wanted to do. She was feeling quiet down and looking toward her partner to help her resolve the toe issues.</i></p>

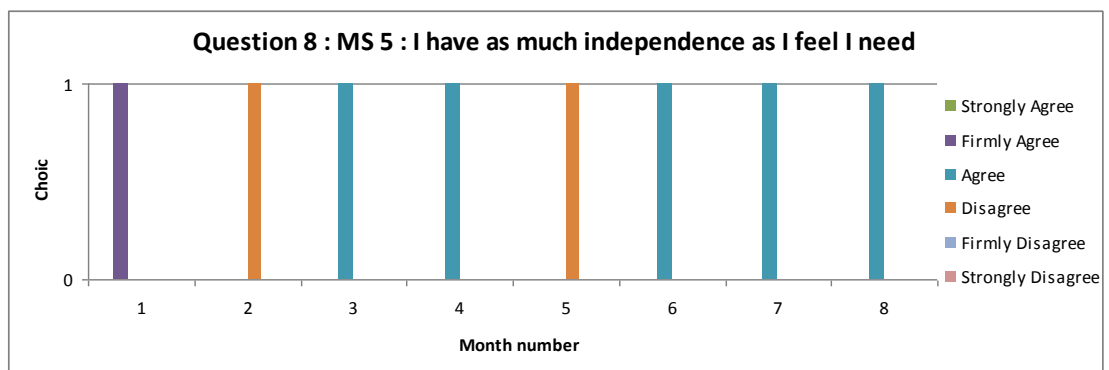
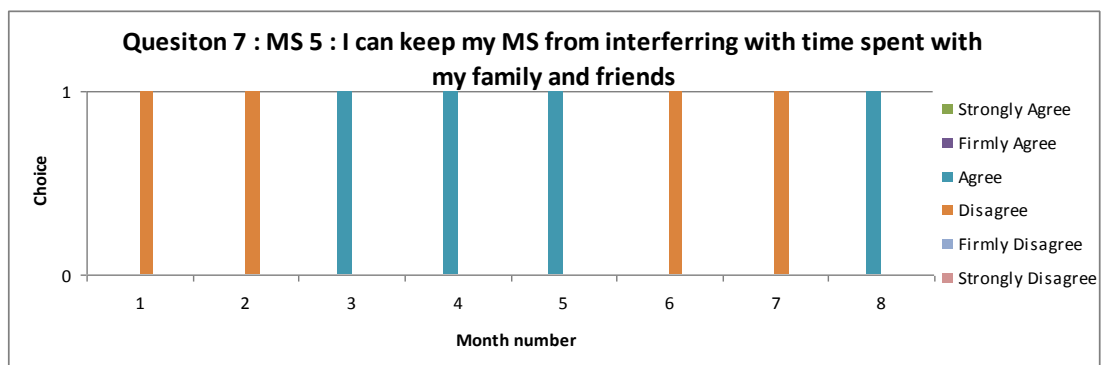
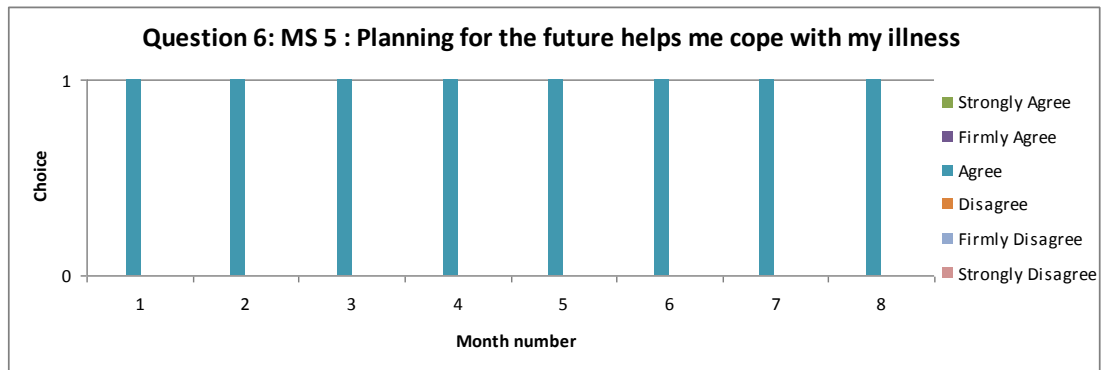
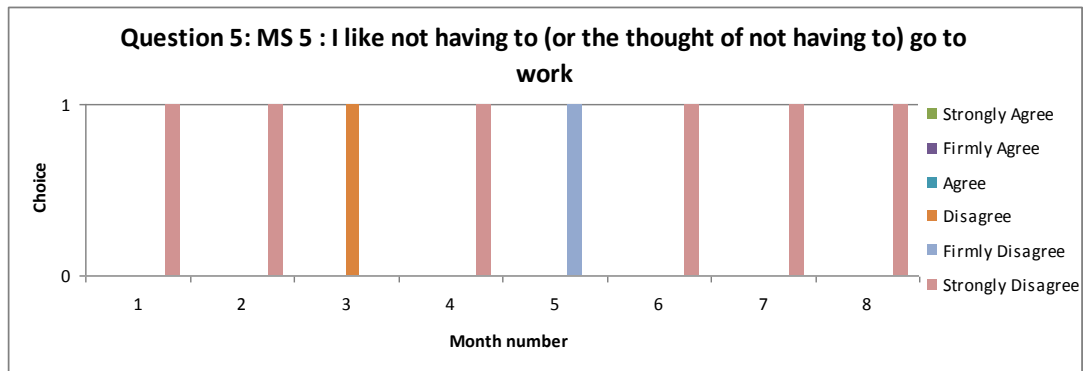
MS 4 MEETING 5	SELF-EFFICACY QUESTIONNAIRE
<p>Last Friday I went to see the chiropodist at last and my toe is as sore as ever. She said the nail needs to come off. So it is planned for the 2nd July. I do not like thinking about it but want the relief. I have had the problem for a year now and It will be done 2 weeks tomorrow.</p> <p>It is like when I was first diagnosed and said Why me and I cried everyday for a year and could not accept it.</p> <p>Even this morning 4 times I have walked into things and am getting a nasty bruise. Normally your brain gets the message but my message does not even get there. Everyone with MS is different.</p> <p>With MS you cannot lead a normal life as you cannot do the things you want to do. I used to have a memory like an elephant but I do not anymore because I cannot remember the simple things.</p> <p>People keep going on about diets and MS but I do not think they make any difference.</p> <p>Next time you see me I will be back to normal with my toe sorted and much more positive and happier</p>	<p>Social Confidence – <i>More positive today as there she had her appointment with the chiropodist to get the toe sorted. Her confidence was back and she was feeling happier and more satisfied in general. She talked about the people she met during her consultation and felt thing were moving forward.</i></p> <p>Independence and activity – <i>She was back to feeling she had the independence she needed due to having an appointment to have the toenail removed she felt back in control. She was still feeling a bit of a failure due to the restricted mobility but could see light at the end of the tunnel. She felt more in control of her fatigue due to some enforced rest with the toe but the social life could be better without the MS and toe problems.</i></p> <p>Worries and concerns – <i>She was still expressing strong worries of her condition getting worse as she is getting more tired and her legs do not feel as strong but her Consultant put that down to her getting older. She was feeling inadequate and reminiscing on the things they did like bike rides, hill walking and things she could not do, but they had been out having a picnic in the woods. The symptoms of MS were making her strongly agree that MS controls her life – this is the strongest this has been but she had fallen in the bedroom and was having urinary problems again.</i></p> <p>Personal control – <i>The roller coaster of emotions had its real ups and downs today as she was positive about some things but other concerns were really getting her down. She was looking forward to her holiday and hoped the MS would not interfere with that but she did feel more in control of doing what she wanted when she wanted to. She was self-managing and doing more cooking and work in the house.</i></p>

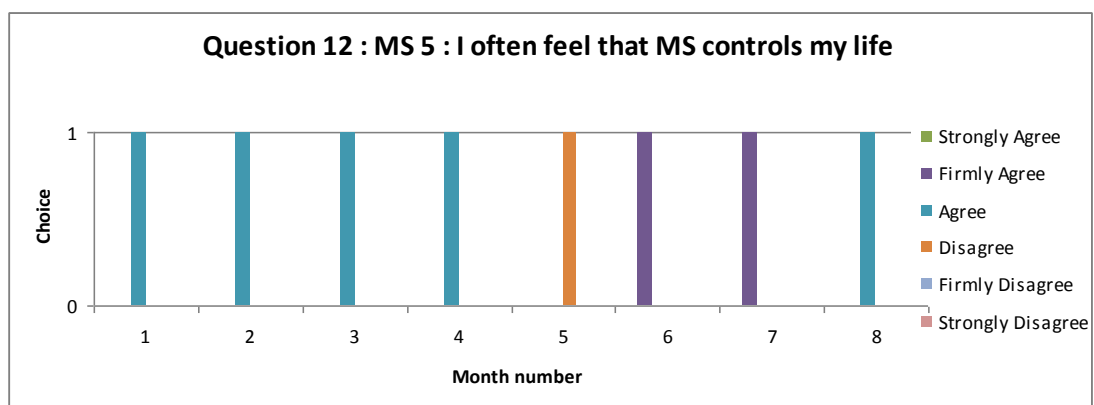
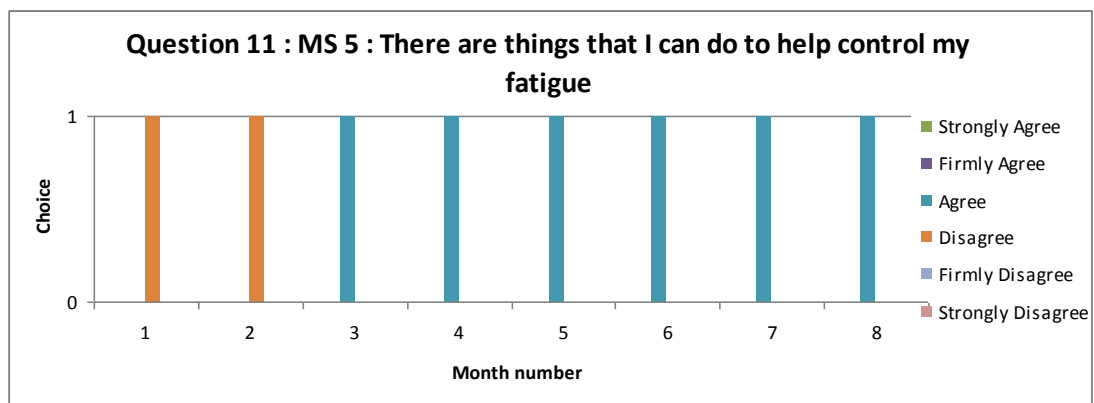
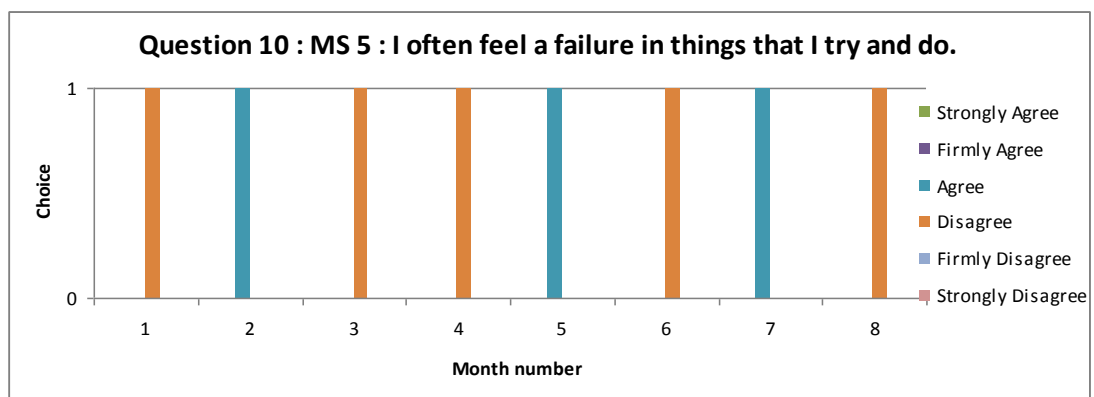
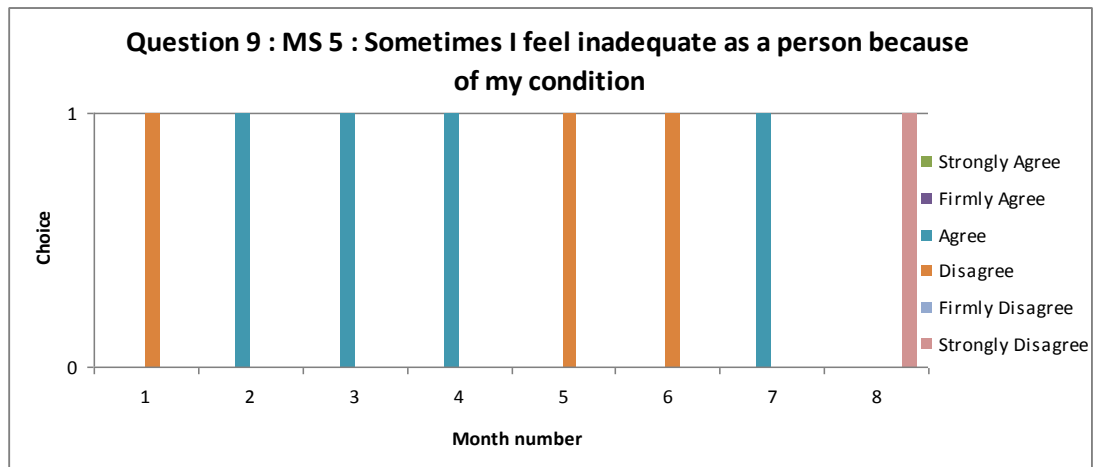
MS 4 MEETING 6	SELF-EFFICACY QUESTIONNAIRE
<p>I have had my toe sorted and the pain is intense and I am pill popping all of the time which I do not like. He said it can take up to 6 months to heal.</p> <p>I cannot wear shoes or slippers just these sandals with my toe out of the front but at least I can drive and can go out & about. MS takes control of everything and I cannot go shopping and wandering off all the time and cannot walk far really. Things are getting worse over the years but that could be age and not just MS. It is frustrating watching others playing with my grandchildren when I cannot. I buy all the games but cannot play them. I used to jump up and get tea and cakes for the family – but now they have to help themselves & learn to understand more. The fresh air is wonderful & I love to be out I would be like a caged lion if I was locked in.</p> <p>I do NOT like going in a wheelchair in fact I hate that.</p> <p>I would not take big risks if I was going to hurt myself or cause any injuries.</p> <p>I want to self-manage my toes and not go back for them to dress it.</p>	<p>Social Confidence – <i>The toe was sorted and she was much more confident and happy and had opted to self-manage her own dressings. She was concerned she would not be able to swim on holiday as she could not get the toe wet.</i></p> <p>Independence and activity – <i>She was not feeling as independent today due to the pain in her toe but she was going out and able to drive but still feeling a failure in the things she tried to do. Her fatigue was in control but she had been experiencing pins and needles in her arms and was worried that she may be heading for a relapse. Her restricted mobility was still frustrating her along with the pain. She stated repeatedly it was her self-determination that made her positive, independent and in control. When she cannot do things it is usually due to fatigue.</i></p> <p>Worries and concerns – <i>Her thoughts of her MS getting worse were less this time which could be due to her Consultant appointments times now being 9 monthly. She was embarrassed at her footwear and not being able to walk far but resisted the perils of the wheelchair as that would make her feel even more inadequate. She was yearning a better social life at this time as due to pain and discomfort she was not socialising as much.</i></p> <p>Personal control – <i>She was back to planning to help her cope with her MS and was striving to limit it interfering with the time spent with family and friends. There were more restriction in her personal control limiting what she could do due to the toe and worries about her MS.</i></p>

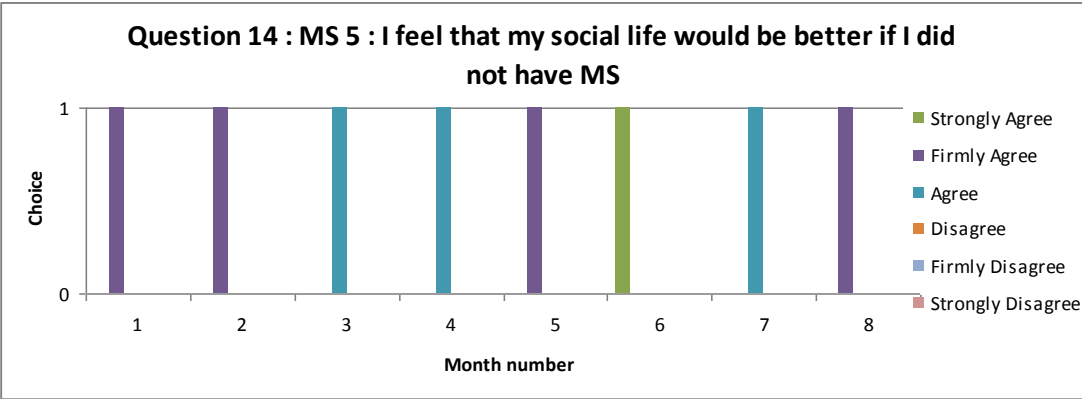
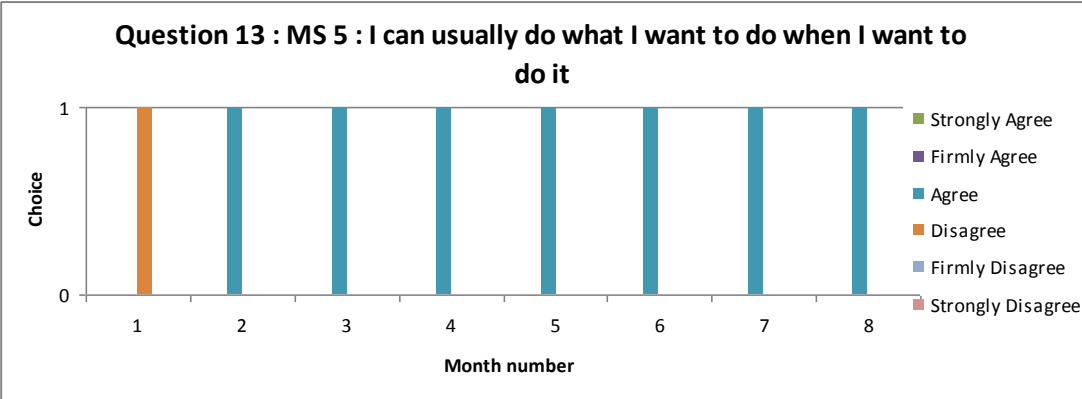
MS 4 MEETING 7	SELF-EFFICACY QUESTIONNAIRE
<p>I am a sun worshipper and I am feeling tired already now the sun has gone. My toe is healing fine & I am back in control and more independent now. The Consultant feels my fitness has kept me healthier & I was pleased about that. My waterworks have been really bad & I keep asking for labstix to test my urine in case of infection but they will not let me. I am still in control but having more difficulty with the steep stairs. A stair lift would just be another nail in the coffin and I am not ready for that yet. I am okay as long as I can drive A to B. I was much more active prior to MS and would like to see it again – in my dreams. I resent the things I cannot do like walking, hill climbing, playing with kids. I self-manage, cope, I am independent & the MS Nurses say it is being positive. Falling knocks your confidence. My family are my life priority and they always have and will be.</p>	<p>Social Confidence – <i>The holiday was enjoyed but the sun has gone which have made her feel less confident as she feels she has less opportunities of meeting new people or going to new places. She is happy and satisfied with the things she is doing during the day.</i></p> <p>Independence and activity – <i>She was still agreeing that she has enough independence and has been driving and going out. She was commenting on how she liked to buzz around and feel busy but recently she felt she was sat back watching others do that but she still felt very much in control. She had been baking for the fete at the church and was busy preparing things for her to help out and raise money. She was fairly active and busy in the home with all of the activities but still resented the things she could not do.</i></p> <p>Worries and concerns – <i>The urinary problems had been bad and she wanted to self-manage the testing of her urine in order for prompt action to be taken in light of her previous kidney problems. But there had been refusal to let her have the labstix but she was going to ask at the hospital as she did not want to risk those problems again when she was in ICU. Her toe was better and she was feeling good about that but worried about getting shoes to suit her feet as she was fed up with sandals. Problems with balance and tripping have been getting her down.</i></p> <p>Personal control – <i>The change in weather and lack of sun was having its toll on her and she felt she was not in the mood to plan for coping with her illness and the recent fall and symptoms were signalling to her a potential relapse. She was doing more socially and her family were coming around but the MS worries were reflecting on her. She was fully self-managing, more independent and much more positive.</i></p>

MS 4 MEETING 8	SELF-EFFICACY QUESTIONNAIRE
<p>I had a fall in the bedroom and I think it might be an advanced warning. It was frightening & I could not find a cause. My urine does smell & is worrying me. They still will not give me the labstix & by the time you have an appointment it is clear again. I want to self-manage this. I said if I die it will be by kidneys that finish me off not the MS.</p> <p>I have looked after myself for 20 years & have self-managed and got on with life & I do not want something like this to knock me off my feet – they know about my previous kidney problems & being in ICU. I know when things are affecting my MS and when it is my kidneys and how they can affect each other – I want control. My holidays are my goals and we keep them on target.</p> <p>The church and our faith keep us positive and able to cope with life.</p> <p>I am very independent and go out & do the things that I want to do. I have much self-determination to cope with everything</p>	<p>Social Confidence – <i>She had been out with her daughter and had an “advanced warning” being very tired and needing to sit down, also another bad fall in the bedroom at home and ongoing urinary problems which had all knocked her confidence. There was fear of going out now due to falling and not finding a toilet in time for her frequency/urgency. She was happy and satisfied keeping busy at home and preparing to make things for Xmas.</i></p> <p>Independence and activity – <i>Still feeling independent but with feelings of strong inadequacy due to her condition and feeling a failure in the things she tries to do. Having graded that she was frustrated at not being able to paint the high bedroom ceiling. Her fatigue was also causing problems and her social life was not as good as she wanted.</i></p> <p>Worries and concerns – <i>Her urinary problems were causing the main worries and anxieties along with the falls and fatigue due to MS. She was really worried about a potential relapse as she had not had one for a long time and this was playing on her mind. She was balancing her independence and dependence with the control battle with MS but stated she was still positive and knew she could cope.</i></p> <p>Personal control – <i>She felt these problems needed to be sorted to help her plan more for the future and stop MS from interfering in her life but she was in control and determined to make the most of things and able to do what she wanted to do.</i></p>



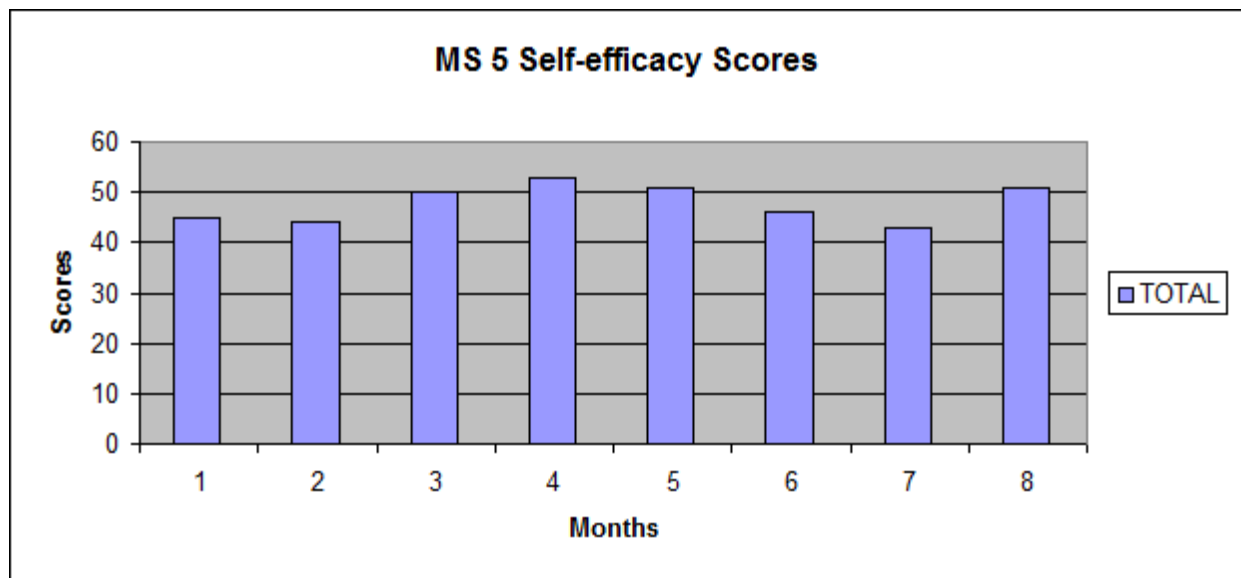






**MS 5
2008**

Question	Month							
	1	2	3	4	5	6	7	8
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3	3	3	3	3	4	3	3	3
4	2	4	3	4	5	5	4	4
5	1	1	3	6	2	1	1	1
6	4	4	4	4	4	4	4	4
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9	4	3	3	3	4	4	3	6
10	4	3	4	4	3	4	3	4
11	3	3	4	4	4	4	4	4
12	3	3	3	3	4	2	2	3
13	3	4	4	4	4	4	4	4
14	2	2	3	3	2	1	3	2
TOTAL	45	44	50	53	51	46	43	51



MS 5 MEETING 1	SELF-EFFICACY QUESTIONNAIRE
<p>The GP thought I was using my symptoms to get out of my final exams. I was in total denial & did not tell anyone until fairly recently, I only came out last year. I still do not really tell people. I was in control & able to continue working and get on with things. I self-manage my injections no bother. I am trying my damnest to combat the symptoms & look after myself. I have to learn to do things in moderation & control my fatigue as MS bites back. I have acquired a lot more knowledge and expertise and how they relate to my symptoms. Fatigue is more than tiredness I do not like doing nothing I like to be busy. My social aspects have changed a tad especially where money is concerned. I am trying damn hard to get a job. My college work in going well and I am enjoying the cookery and biology. Looking for jobs keeps me really busy. I totally look after myself and my flat and am able to self-manage, plan what I am going to do and meet my targets. I do not overdo things as you pay for it.</p>	<p>Social Confidence – <i>Confident person who enjoys meeting people, going to new place and keep himself busy and happy/satisfied during the day. He has a good social network of friends and enjoys the networking internet sites.</i></p> <p>Independence and activity – <i>He is desperate for work and is trying hard to find a suitable job as lack of money is affecting his activities. He is physically active and totally independent, able to drive and travels a great deal to see his girlfriend. He does not feel inadequate or a failure due to his MS but does feel his social life would be better but most of that is money related.</i></p> <p>Worries and concerns – <i>He states he does think about the future and is slightly worried that his MS might get worse. He is sometimes worried about his staggering walk which he is embarrassed about in public place. He feels to some extent MS does control his life, he has to listen to his body and take notice of any symptoms which he is concerned about in terms of limiting what he can and cannot do at times.</i></p> <p>Personal control – <i>He sets goals and targets and plans for the future which he feels helps him cope, MS does not stop him spending time with his family and friends. He has a positive outlook on life, is self-determined and feels he is able to work and a job search is taking much of his time. He states he is totally self-managing and lives and looks after his flat which was very clean and tidy. He is trying his best to combat his symptoms and stay in control.</i></p>

MS 5 MEETING 2	SELF-EFFICACY QUESTIONNAIRE
<p>I had a relapse on 12th February my eyes were peculiar & my balance & it progressed from there. I could not focus. I had a few days off driving.</p> <p>I keep forgetting things in my short term memory and it goes through phases.</p> <p>I am desperate to get a job but do not know if I shoot myself in the foot telling them about my MS—to qualify as disabled.</p> <p>I have a healthy diet with fruit and veg and I do all my own cooking which I enjoy.</p> <p>I am able to ask questions and feel much empowered and understand what the professionals are saying & have good discussions with them to manage my MS.</p> <p>I feel in control of my appointments & my time with the healthcare professionals.</p> <p>I keep myself fit with all my gym activities.</p> <p>We went to Amsterdam for a long weekend and walked for miles and really overdid things I was feeling pretty dreadful and really fatigued & have really paid for it</p> <p>The whole weekend was messed up from beginning to end it was very long and exhausting – I am just recovering now.</p> <p>I am very routine based. I cope with the unpredictability & uncertainty as it comes.</p>	<p>Social Confidence – He had a relapse later in the day after our last meeting and that had knocked him for a few days but he felt good again and his confidence and abilities had returned. He was being more cautious not to overdo things which he found a bit frustrating.</p> <p>Independence and activity – Still looking for work but had not been feeling as independent and felt a failure due to the relapse. His fatigue was also limiting his activities and social life but he saw this as temporary. He was still able to do most things himself but had a few days of optic neuritis when he could not drive and relied on his family for transport.</p> <p>Worries and concerns – There were some concerns that his MS could get worse but he was back in control and was feeling more than adequate. He was not embarrassed in public places but still felt MS had some control but his own determination and positive nature would see him through. He had overdone things on a recent weekend away which resulted in MS biting back and his slower than planned recovery. This was a concern but he was determined to fight it but not overdo things too much again.</p> <p>Personal control – He was still planning which helped him to cope but found MS was interfering more with the time he spent with his family and friends. This was not stopping him from doing what he wanted to and he was back at the gym and doing Pilates seeing this relapse as a temporary setback.</p>

MS 5 MEETING 3	SELF-EFFICACY QUESTIONNAIRE
<p>I enjoy challenges but my big goal currently is to get a job.</p> <p>I am able to manage without overdoing things I pace myself and am in control.</p> <p>I am very independent & determined.</p> <p>I am still going to the gym & my Pilates which helps my balance and coordination.</p> <p>The visual disturbance during my last relapse makes me more cautious but it is part of MS & I have to manage it.</p> <p>MS Life made me realise there were a lot of people with MS who were much worse than me which made me appreciative.</p> <p>It was good to meet other people with MS.</p> <p>I did wonder how I might end up maybe in a wheelchair or needing mobility help. I cannot say that I do not have future fears.</p> <p>I can do most things myself & I am fit.</p> <p>My girlfriend knows all about MS & copes with it fine & asks questions about it.</p> <p>I do memory tests but sometimes the cognitive issues are beyond your control.</p> <p>I do take some risks but am safety aware.</p> <p>I am fully engaged & want to know about my MS & want I am able to do. I am empowered to use my knowledge & expertise. I adapt to changes as & when.</p>	<p><i>Social Confidence</i> – <i>There was still confidence in meeting people and he had enjoyed the MSS conference and met other people. This had made him feel good as he does not need mobility aids as yet but it opened his eyes to the future which made him determined to maintain his mobility as much as possible. He was feeling happy and satisfied feeling he was busy during the day.</i></p> <p><i>Independence and activity</i> – <i>Work was still his main challenge through his independence and job seeking. He was no longer feeling a failure but positive and wanting to move forward with caution due to his visual problems. His fatigue and social life were back in control and he was feeling good about himself in keeping up with the gym.</i></p> <p><i>Worries and concerns</i> – <i>The MS Life conference has made him reflect more on the future and potential concerns about mobility. His memory has also been causing him some cognitive problems but he is doing memory test and computer games to try and improve that. He feels he is engaging well with MS and wants to be totally self-managing as long as possible. He feels able to adapt, integrate and adjust to changes but worries that this may not always be the case but it is about taking a day at a time sometimes.</i></p> <p><i>Personal control</i> – <i>The relapse did knock him and he blamed his lack of control on his weekend away and is planning better to cope with his MS. He is enjoying controlling the time with family and friends and doing what he wants to do to feel in control.</i></p>

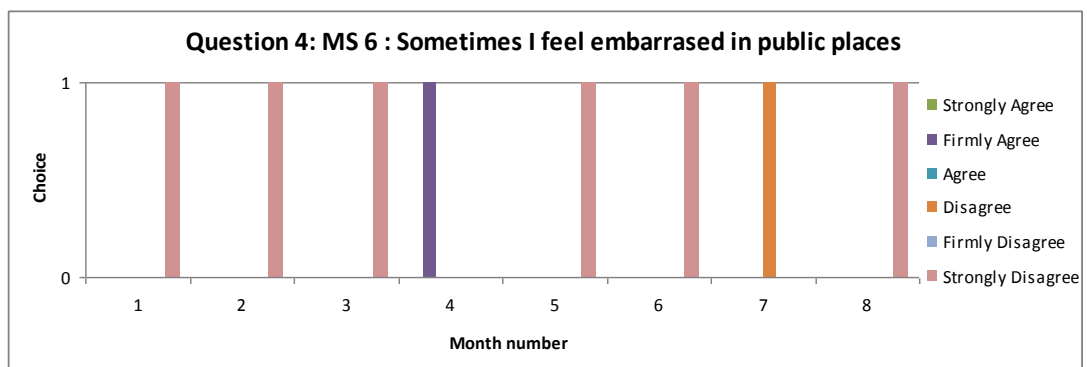
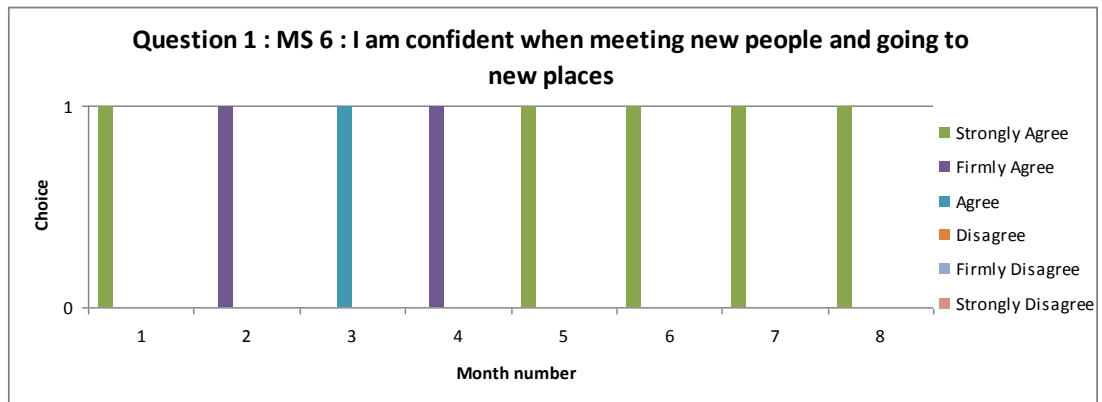
MS 5 MEETING 4	SELF-EFFICACY QUESTIONNAIRE
<p>I have been feeling a bit depressed I really need a job & have for over 2 years & this is really getting to me I need work. I have spent most of the time since we last met going through potential job opportunities including discussions with Job Centre Plus & the Shaw Trust. It is a balance between life style & what suits the MS and not putting myself or others at risk. I want to stay in the NE. I did my advanced DVLA driving test & received an excellent report & to drive both manual and automatic cars. My car is my independence & is important to me and being able to get out & about. I have kept a diary since my early symptoms & have recorded the main events & I would like to share this with you to see my MS journey. The lack of a job and money is really getting me down but it is not for the want of trying I am exploring all avenues. I am still positive and confident and well able to look after myself and to manage my MS but I feel I need to do more as I am getting bored and really want to work. Meeting other people will help me more.</p>	<p>Social Confidence – He stated that “things have been, dare I say occasionally indifferent, not badly so but I have noticed a couple of things but the big one I would say it some kind of depression. I would not say I felt massively depressed but when I was in the shower I thought Christ I am 30 and I have got no job and that played on me for a bloody long time because I really do want to work you know. I have not had any luck at all for over 2 years and that is predominantly due to the MS and its affects you know” He has been feeling lethargic and withdrawal. He has not been to the gym as he has not felt up to it. He states he is still confident but dissatisfied with his daily routine and not feeling useful.</p> <p>Independence and activity – The lack of success in the job seeking is taking its toll as he really wants to work and maintain his independence. He is not feeling a failure but is feeling inadequate and feels maybe being honest about the MS is halting his career. This is getting him down and curtailing his activities but he is using his resources and contact to find employment. He spent most of today’s meeting discussing this and it was hard for him to focus on other things.</p> <p>Worries and concerns – His main worry is the lack of a job and financial concerns. He feels the MS has too much control in preventing employment but he wants to demonstrate what he can do and is concerned about getting the opportunity to prove this. He feels the cognitive problems may be associated with boredom and social isolation. He worries the steroids could have caused the depression.</p> <p>Personal control – He is planning for his future and feels he is doing all he can but is remaining positive and managing himself well.</p>

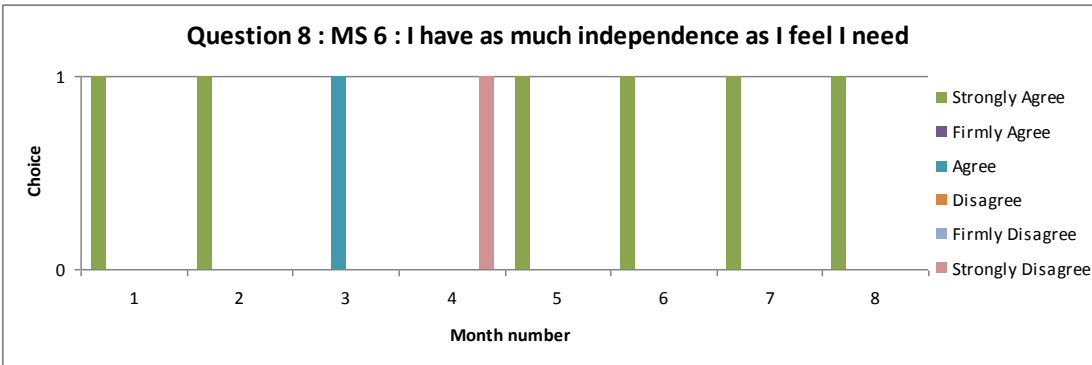
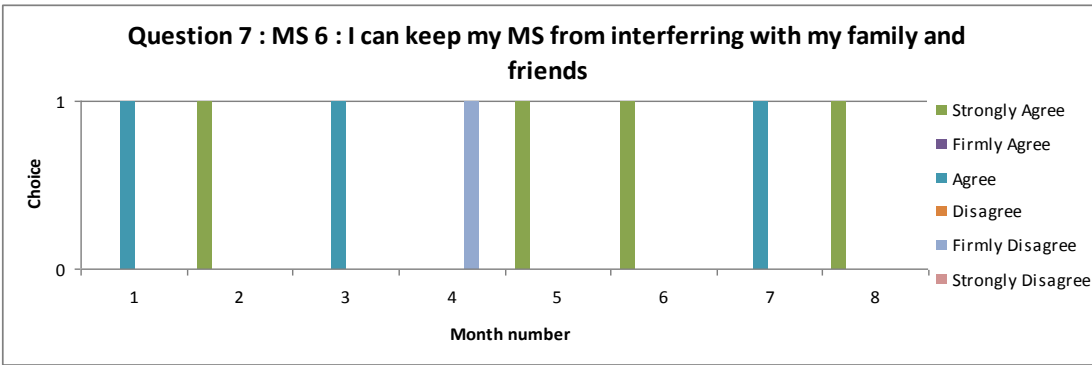
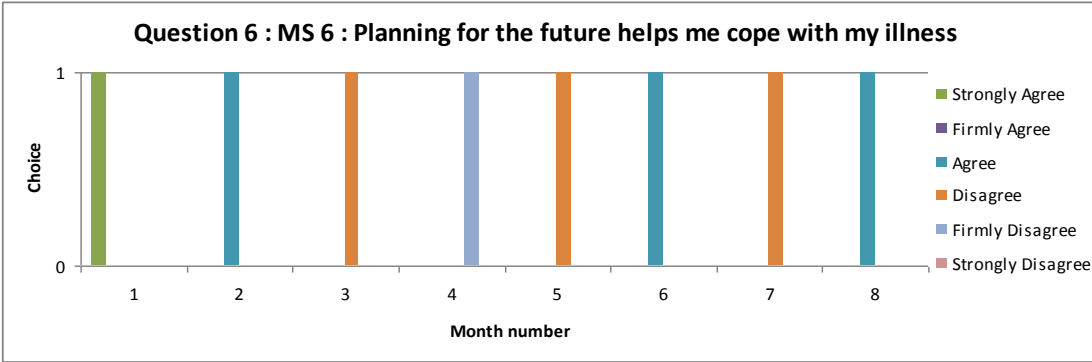
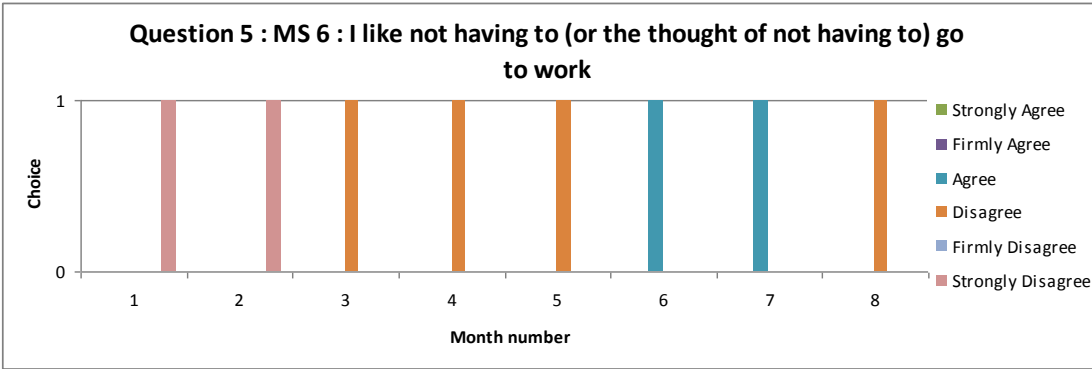
MS 5 MEETING 5	SELF-EFFICACY QUESTIONNAIRE
<p>I have been to Arizona and coped very well with the heat & had a great time. I am still going to the gym & doing Pilates but things have been busy lately. Experience wise & job wise maybe my future is not in the NE & I may have to start looking further afield to ensure I get a job and increase my income. I stepped out of denial when I came back to the NE – I do have MS and that is that. It is hard to accept what you can & cannot do but I try to hold onto things but you have to pay for it over the next few days. I try to recognise my limitations & learn the lessons but it can be annoying. It is frustrating because if I did not have MS I would not think twice about most things. I do not like being saddled with MS I still know who I am and am very much in control. I plan ahead & set goals to make sure my mind is active. I like to keep my place clean & tidy. My independence & determination help me cope with my MS & manage my flat. My strategy is to cope & plan things into my routine and make the best out of the time that is available to me.</p>	<p>Social Confidence – Today things were much better and the confidence, happiness and satisfaction had returned. He had surprised his parents by going to the USA on his father’s birthday and a good time was had by all.</p> <p>Independence and activity – Possibilities were looking up on the job front and he had a busy time with travelling, weddings and looking after himself. He was feeling good about himself; fatigue was in control as he was pacing himself with better planned activities and back to the gym. He feels he looks after himself well and his social life has been better lately but there is still room for more improvement.</p> <p>Worries and concerns – He felt his MS was in control, felt good in public places, felt adequate as a person and he was back in control of his life and MS. He felt the trip to Arizona had given him confidence and he coped well with everything. He feels his self-determination and independence helps him cope with his self-control but does have some concerns for the future in case this would not always be the case. But determination would see him through.</p> <p>Personal control – Planning with his goals and targets helps him cope with his MS, stops it interfering with his family and friends and lets him do what he wants to do. His strategy is to remain personally in control and make the best out of his life and a job would help him to feel more valued, his finances and meeting more people on a daily basis.</p>

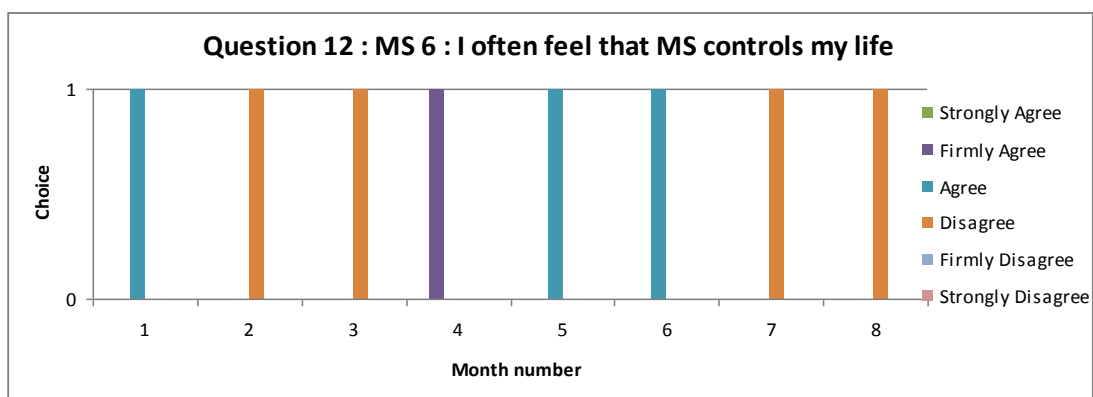
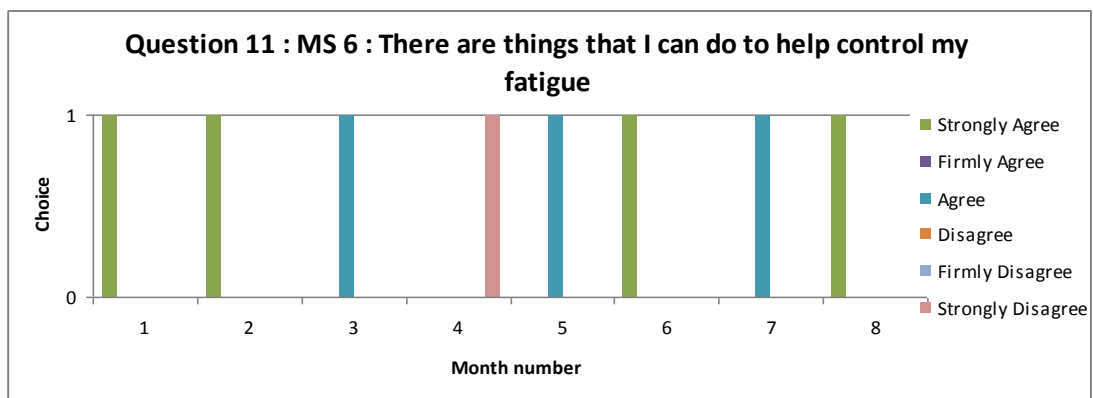
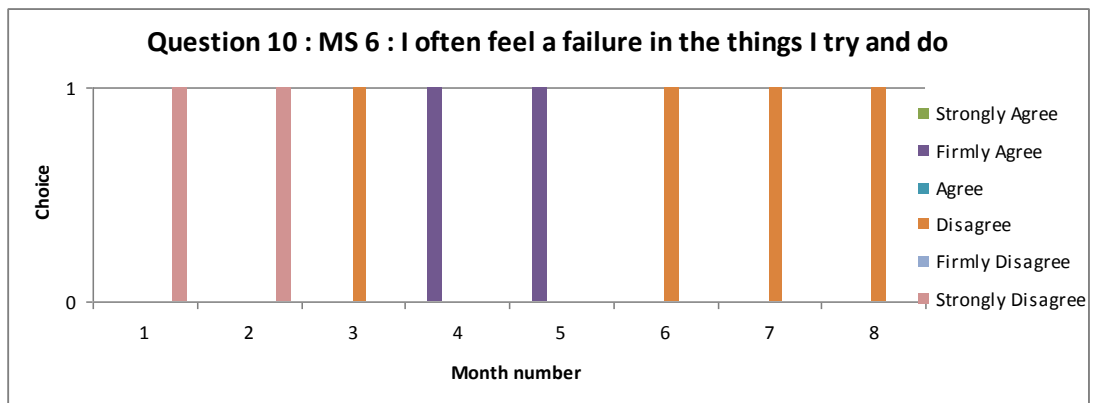
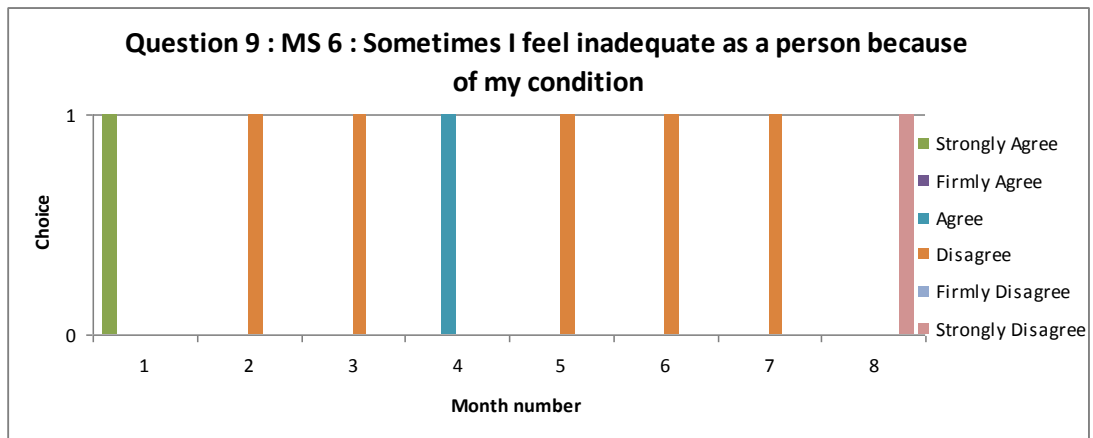
MS 5 MEETING 6	SELF-EFFICACY QUESTIONNAIRE
<p>I have been looking for jobs & there may be a couple of opportunities at last. I discussed my symptoms with my Consultant & we decided to increase the dosage of my DMTs from the next batch. I feel my confidence it has even been due to the job situation & I am feeling that I would do anything just to get out to work. I do what I can to combat my MS & stay on top of the changes that do occur. I do my exercise, have a good diet & look after myself but am desperate for a job. I remain positive in my outlook and ability to manage my MS. Fatigue is important in self-management. It is about pacing yourself & doing things you can do rather than pushing yourself & overdoing things as MS always bites back I am independent & do not feel dependent on anybody as I totally self-manage. My independence was most important to me before and now after MS. You cannot stop or fight MS but you can work with it to maintain independence. Thankfully I do not have many bad days & on a good day I go to the gym, do more in the flat and work on my computer.</p>	<p>Social Confidence – Again he was feeling good and confident but has another knock back on the job front and was not feeling happy and satisfied with what he does during the day. He feels a job would increase his confidence and help him more than anything else at the moment.</p> <p>Independence and activity – He is still feeling independent and totally self managing with everything and feels on top of things, he does not feel a failure and is coping well with his fatigue. He has not been seeing his friends as much and thinks this may be due to him travelling to be with his girlfriend as is trying to encourage her to come to Newcastle more so he does not overdo things with the travelling.</p> <p>Worries and concerns – The Consultant is planning to increase his DMTs to prevent further relapses and he is concerned that it will be the maximum dose he will then be on. He is feeling good about himself but still worried about the lack of a job and feels MS is controlling that. He is going to be best man at his friend's wedding and is looking forward to that and hopes he is able to do that well and MS will not get in the way.</p> <p>Personal control – He is continuing to plan well which is helping him cope and keep things in perspective and stopping MS from interfering with his time with family and friends. He is doing what he wants to do in moderation but feels he is in control, positive and his determination will see him through. He is back at the gym and enjoying getting back in shape and looking after his wellbeing.</p>

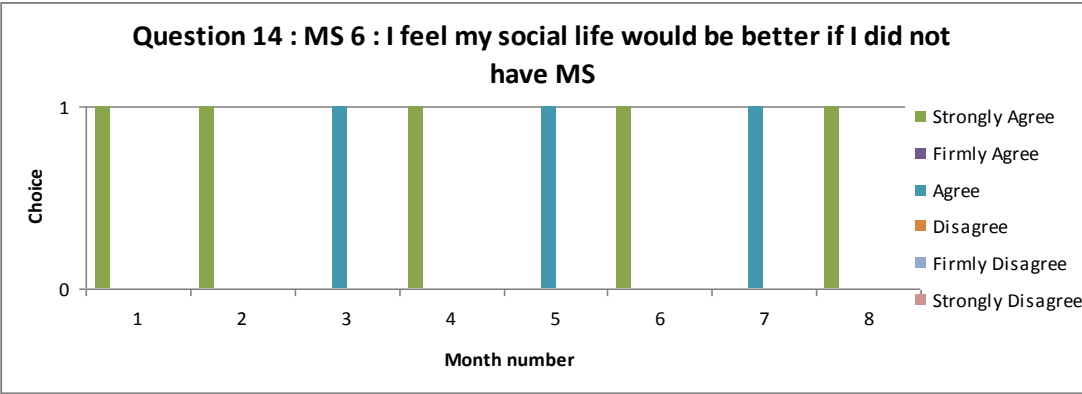
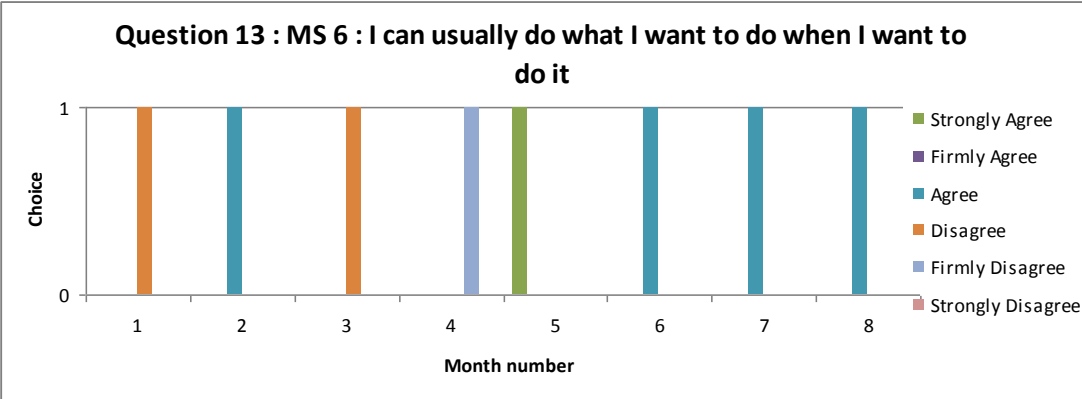
MS 5 MEETING 7	SELF-EFFICACY QUESTIONNAIRE
<p>I am getting quite bored and annoyed with not having a job I am really desperate. I had great day as Best Man at my friend's wedding since we last met.</p> <p>My balance has dipped a bit but it is still within my control & I am going to the gym My current job is my job hunt & it is taking all of my time at present.</p> <p>Lately I have been feeling like a bit of a recluse I have not been out much at all. I have to pace myself better & need to sort myself out & spend time with friends. I am trying to combat my memory problems with computer games.</p> <p>It all seems a bit of a Catch 22 at the moment I really need to sort myself out. The worst thing I feel with my MS is my memory because I forget things despite having tools to help me.</p> <p>I am still the same person as I was before MS but I am getting older but I am still able to take good care of myself & my life. You have to listen to your body but be in control and always be positive at all times. I set myself goals and targets and weigh up the benefits against the potential costs I am a very confident person.</p>	<p>Social Confidence – <i>He is annoyed about the job front but the best man's speech went well and he is feeling confident, enjoyed the wedding and meeting new people. The lack of job is making him dissatisfied and unhappy with his days which are spent unsuccessfully job seeking.</i></p> <p>Independence and activity – <i>His independence is still there and he is pacing himself in terms of his activities and maintaining control of his MS. He is feeling good about himself but is feeling a bit socially isolated due to his constrained activities but is going to the gym and staying fit. He is still active in the flat and totally self-managing.</i></p> <p>Worries and concerns – <i>The cognitive problems particularly memory wise are causing ongoing concerns and he is trying to combat them. He is worried about his MS but feels he is listening to his body and controlling things. He feels MS does have some control and he has to work with it and not against it as it always bites back. "6-7 months ago when you first started to come to see me I think MS was a smaller part of me then, but it does seem to be becoming a bigger part again, because of the same good reason the lack of a job which I still have not got"</i></p> <p>Personal control – <i>He has goals and targets and is positively feeling he is getting a cost benefit balance. He feels he is coping better this way but MS still interferes as times. He can do what he wants to do as long as he recognises the limitations and takes notice of what he is doing. He is still trying to manage his cognitive problems and feels his memory lets him down at times.</i></p>

MS 5 MEETING 8	SELF-EFFICACY QUESTIONNAIRE
<p>I am doing the ECDL & am determined to get it done and to pass it.</p> <p>Now I have registered for a 5 week course with Employment Opportunities – it is called Job Ready with a high success rate I went to see a band last night with my mates which was great.</p> <p>DMTs helped me do more, I have always been self-caring but they helped me to more so and be more in control of my MS & cope with unpredictability & uncertainty. People tell me I am a better man & have a better personality now that my MS is open I am confident, believe in myself, have good self-esteem and capabilities.</p> <p>I believe I can overcome the challenges of MS & overcome most things at my pace. In the main I am happy with my quality of life but a job & money would help me.</p> <p>I feel in control & able to manage things as they come & use them to fight MS.</p> <p>MS is in my world, I have it and I have learnt to live with it, it is one of life's cards shall we say. It has not changed me a massive amount but it part of my world but does not control it or me. I see myself as one of the trials of MS.</p>	<p>Social Confidence – Confidence was good he said due to meeting people and attending the Employment Opportunities Course which was making his days better. He was also occupied doing the ECDL training which was also helping.</p> <p>Independence and activity – Still job seeking, feeling he has enough independence, is very adequate and controlling his fatigue. He is trying to improve his social life, is busy with his studying activities, the gym and self-managing his care. He feels the higher strength DMTs are helping in the control of his MS in coping with the uncertainty and unpredictability along with his self-esteem and capabilities. He feels he can overcome the challenges that MS places upon him as he feels so good about himself.</p> <p>Worries and concerns – He is concerned what happens in the future if again he reaches the tolerance level of the stronger drugs and what happens next. MS is still partially in control but he feels he can take more control from it as he feels good, happy with his quality of life and determined to stay on top of things. He is worried about all the travelling he is doing to see his girlfriend but is trying to decide their future and is balancing that with more time with his friends. MS is a big part of his world but it is not his world there are lots of things he needs to balance, even if it means taking calculated risks to allay his worries and anxieties.</p> <p>Personal control – He knows his condition will progress but feels his personal control will manage that if he can continue to stop it interfering and keep it at arms' length by listening to his body which he knows best and feels as expert in his own MS. He states he will remain in control and he knows best.</p>



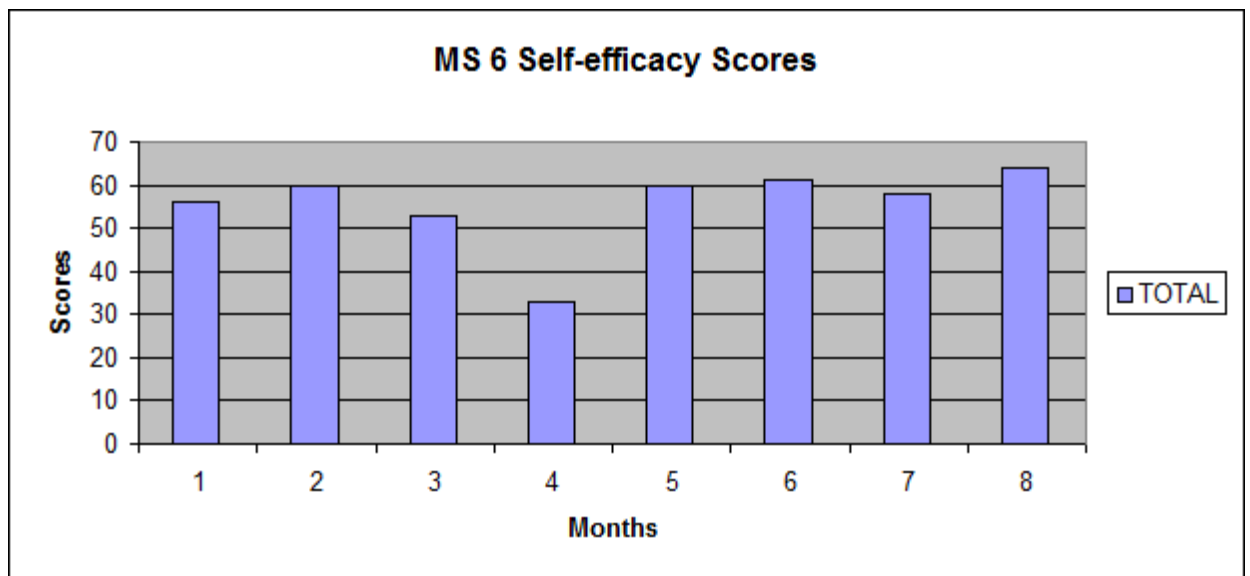






**MS 6
2008**

	Month							
Question	1	2	3	4	5	6	7	8
1	6	5	4	5	6	6	6	6
2	4	4	4	5	5	4	4	5
3	3	3	3	2	3	3	4	3
4	6	6	6	2	6	6	4	6
5	1	1	3	3	3	4	4	3
6	6	4	3	2	3	4	3	4
7	4	6	4	2	6	6	4	6
8	6	6	4	1	6	6	6	6
9	1	4	4	3	4	4	4	6
10	6	6	4	2	2	4	4	4
11	6	6	4	1	4	6	4	6
12	3	4	4	2	3	3	4	4
13	3	4	3	2	6	4	4	4
14	1	1	3	1	3	1	3	1
TOTAL	56	60	53	33	60	61	58	64



MS 6 MEETING 1	SELF-EFFICACY QUESTIONNAIRE
<p>I have a very strong mind & I did not accept MS but I did say to myself this is inevitable and take each day as it comes. In my mind I am not giving into MS, it is just the body cannot do what the mind wants it to do.</p> <p>I like to be independent and do most things for myself – if I need help I ask for it I am very much in control,</p> <p>I think I am extremely confident and very able to self manage myself.</p> <p>I was always a keen gardener & before I became incapable I made it very low maintenance so that the family could do it. I am doing well due to my previous physical ability and my mental ability. My strong mind controls my life & body. Every February I have the worst relapse of the year – my body seems to say look you are having a couple of weeks off now. My family are very supportive and help to keep me empowered, they will only do things when I ask them and they include me in what is going on all the time. I am not fully in a wheelchair yet; I can stand and walk using the furniture and can take up to 10 steps. My scooter helps my independence.</p>	<p>Social Confidence – <i>A very confident man who was very outgoing, enjoyed company and stated he was making the most out of his life and not dwelling on MS. He was very friendly and willing to share his journey and help in the research in anyway.</i></p> <p>Independence and activity – <i>Despite limited walking and mainly being active in a wheelchair or on a scooter this man went weekly to the job centre looking for suitable employment. He was very independent and felt in control. He stated he has never felt like a failure as he does everything he can himself, he controls his fatigue but feels his activities and social life would be much better without MS. He really misses being able to undertaken his sporting activities and physical hobbies.</i></p> <p>Worries and concerns – <i>He stated he does have worries about his MS getting worse and that every year in February he has a big relapse from which he does not have a full recovery and has bad reactions to steroids. He has no embarrassment in public places, but does strongly feel inadequate because of his MS. He feels MS does control him life to some degree but feels positive at all times and feels empowered.</i></p> <p>Personal control – <i>Planning helps him cope with MS and stops it from interfering with his family and friends. Due to his physical limitations he is not able to do what he want to do as he may need support at times but feels that he controls that and things are done at his request.</i></p>

MS 6 MEETING 2	SELF-EFFICACY QUESTIONNAIRE
<p>I did not feel good in myself but the steroids always do that they knock me for six for well over a week – I could not move. I have a good memory & an active mind. I was totally fatigued, lacked coordination and movement for over one week. Slow deterioration is like age it creeps up on you which is easier to cope with. I take vitamins and do exercises following this Irish lad who cured his own MS. My quality of life is acceptable – I cannot do all the sports I used to but it does not stop me going out on my scooter meeting people, bird watching & going to the park. I have a healthy diet with lots of fruit and vegetables and look after myself. My independence has been hindered by the professionals as I have been waiting over 2 years for an agreed wet room & downstairs bedroom. They supply little things but lack coordination on big things. I am of the frame of mind sitting around with others with MS makes you think more about it instead of getting on with your life. I read, use the computer and play chess internationally which keeps the mind active – I am above average at chess.</p>	<p>Social Confidence – Firm confidence in going out and meeting people and keeping busy during the day feeling happy and satisfied. He does not feel sitting around with others with MS helps his social confidence as they tend to dwell on things and not get on with life.</p> <p>Independence and activity – He still maintain his strong feeling of independence, not feeling a failure in what he does and can control his fatigue by keeping occupied and having lots of visitors during the day. He goes out on his scooter when the weather is okay and visits the park bird watching, shops and pays the bills and visits friends. On rainy days he reads, uses the computer and competitively plays chess.</p> <p>Worries and concerns – He has just been for a 3 day treatment of steroids to prevent his annual big relapse but they steroids have had a bad affect again which has made his mobility harder. He is concerned about the impact they have but agreed to try them prospectively to see if they would help along with his DMTs and feels they were worse last time. He feels he controls his life not MS but the steroid do interfere.</p> <p>Personal control – He does continue to plan and likes to feel in control which helps him cope with his MS and he can stop it inferring with family life. He pleases himself what he does each day and his partner leaves everything ready for him after helping him up each day. He totally self-manages his hygiene, tablets, injections and activities. His scooter and crutches are left in place for him and he walks to the bathroom and self-transfers to drives his scooter. He feels he makes the most of his life and it happy.</p>

MS 6 MEETING 3	SELF-EFFICACY QUESTIONNAIRE
<p>In my mind I am still not back to the same as I was but am climbing the ladder to get back to pre-relapse – heading that way. I am self-managing and getting around the house and out on the scooter. I had a great birthday & we went to the coast & had fish and chips & enjoyed it. I am as fit as I should be & physically holding my own at the moment. I have a strong mind which controls my physical weaknesses - it drives them. I feel my self-determination drives me to do as much as I can; I want to be as independent and to self-manage as much as I possibly can. I am empowered to do what I can which is living with my MS and being in control. With MS you can exercise to a level but if you go above it MS will bite you back – If you bite MS it bites you back so you have to know your physical capabilities. I feel I am a person with as much control as I need and I can exercise that control within my network of family & friends. I take each day as it comes and plan my activities accordingly. I have not taken risks for a long time – I am so determined & positive I do not need to take risks.</p>	<p>Social Confidence – <i>His confidence was not as strong today due to the ongoing after effects of the steroids but he felt physically wise there were slow improvements but he been going out on his scooter. He was keeping busy in the house so still felt happy and satisfied.</i></p> <p>Independence and activity – <i>Still feeling he has the independence he needs and his friends have been visiting him so he has been occupied most day. His mobility has not returned to what it was as yet as he is still needing more transfer support from his partner and family. He is doing as much as he can, doing his arm and leg exercises. He has been supervising the gardening which he taught his partner and step-daughter to do when he was still physically mobile.</i></p> <p>Worries and concerns – <i>He is worried at his slow recovery rate but feels it just needs time and disagrees that MS controls his life. He does worry about his partner who has to help him more with lifting him and she has had back problems before. His step-son who does help is planning on going to Australia for a year and that is playing on his mind, although he does feel it is a great opportunity for him. He does not believe in worrying and thinks that most 80% of worry is unfounded.</i></p> <p>Personal control – <i>Presently he does not feel he can plan much but is taking each day at a time until things are back to normal. He cannot do as much as he wants to but is listening to his body and managing as he can. He stressed his positiveness, determination and continued self-management.</i></p>

MS 6 MEETING 4	SELF-EFFICACY QUESTIONNAIRE
<p>I have had a bit of a relapse and have not been well lately it is probably a little set back, a reminder that it is still there and MS is still in charge.</p> <p>My movement is restricted in my right hand and leg but I can still use my hands to hold onto the furniture & walk to the bathroom. I can still self-manage & wash, shave and everything. I am still in control and doing everything it is doable.</p> <p>I played rugby for 27 years and I still watch it and would love to play again.</p> <p>I fell upstairs again but did not hurt myself because I learnt to fall doing judo.</p> <p>You have got to make the most of life and look after yourself which is what I do, remain positive and as independent as your condition allows you to be.</p> <p>People with MS need to be given all the information that they need to manage their own condition.</p> <p>I have an excellent relationship with my GP he understands me and my MS and he knows me and my family and has a much better understanding of my situation</p> <p>The good weather is great I am in control of my scooter & visit all the hot spots.</p>	<p>Social Confidence – Again he states he is more confident but feels he has possibly had a relapse as he is not as good with stiffness and lethargy. He feels the steroids have made him worse not better and MS is warning him that it is still in charge.</p> <p>Independence and activity – For the first time he strongly feels he does not have enough independence. He is able to self-manage his hygiene and toilet needs, his tablet and injections but not much more than that at present. On some occasions he is managing to get to the bathroom walking but it is becoming harder and he is asking for the flow-chair with assistance. He had a fall and did hurt himself a bit but bounced back as he states he usually does. His leg and arm movements were more restricted and he stated he felt really stiff at times but was trying to continue his exercises.</p> <p>Worries and concerns – With this setback he was more concerned about his future and his MS getting worse and was feeling more embarrassed in public places and did feel inadequate at times. MS was more in control at this time which he was concerned about but felt it was only temporary.</p> <p>Personal control – He did not feel as in control and could not plan too much further until he knew what was happening to his MS. He also felt it was having more of an impact on his family and friend as he did not look as good but was trying to convince them of his positiveness and determination. He felt his GP was a great support and he helps with his understanding and knowledge of MS and this temporary setback.</p>

MS 6 MEETING 5	SELF-EFFICACY QUESTIONNAIRE
<p>I am still not too good but I do not think it is my MS but a bug or something. I am still maintaining my control and independence but it has knocked me for six but I will get over it. It is frustrating waiting to hear about our extension but it is a case of wait and see and yes as normal we kept in the dark The acceptance of MS grew with the progression and you learn to live along side it but you do not fight it but make changes to your independence & control as you go along. There are physical barriers but nothing is an obstacle – Were there is a will there is always a way. Again my strong mind. 80% of worry is unfounded so why worry life it too short – my good philosophy. MS has made me a gentleman of leisure it has stopped me doing what I liked doing but I can instruct others in a supervisory capacity – you have to adapt you know. My family work with me to allow me to support me to manage my MS. I want to maintain my independence and empowerment as much as I can to self-manage my MS.</p>	<p>Social Confidence – <i>Today he is back to feeling strongly confident and apart from feeling stiff and a bit weak he feels much better and feels it was not the MS but some bug he picked up – but he still does not look as good as he was. He feels more satisfied and happy with his days and keeping busy.</i></p> <p>Independence and activity – <i>He strongly agrees his independence is back to where he wants it and he is back in control of his life and activities. He is still feeling a failure in what he tries to do but is putting that down to a chest infection. He feels his fatigue is under control and his social life is improving.</i></p> <p>Worries and concerns – <i>He is still concerned about the future and wishes his wet room and downstairs bedroom where there as they would make things easier. He is feeling more adequate with his MS but still sees it having some control. He feels because he had time to have a gradual acceptance of his MS post road traffic accident that this has helped him not to worry or be concerned about MS. It has helped in the adaptation, integration and adjustments he has made in his life and feels he can maintain.</i></p> <p>Personal control – <i>He is looking ahead but not planning to the same level as he was due to the uncertainties and unpredictabilities he has been facing recently. He feels he is back to stopping MS interfering with his family life or with his friends as they do not talk about it and he has things under control. He feels there are physical barriers but that nothing is an obstacle when there are ways around it which he plans and orchestrates.</i></p>

MS 6 MEETING 6	SELF-EFFICACY QUESTIONNAIRE
<p>I am still weak & fatigued but starting to come out of it now. It is not my MS. My walking has been restricted and I can only go back and forth to the toilet. I have to push myself it is mind over matter but the strong mind means control. The extension saga is getting me down & it has been another frustrating 2 weeks. My GP often sits in with the Consultant to get my information first hand. I am still exercising my arms and legs just to keep moving and keep fit. You do not need to be pushed to do things your own self-determination tells you what you can do & when to stop. I am able to control where and when I want things and if I cannot personally do it I can ask for help to get things for me. I have always worked on my strong mental ability to give me control over my physical abilities and that is what has kept my independence, power & control. My bad days are when I am totally fatigued and have to rely on someone else because my arms & legs are not good & don't do as they are told when they are told.</p>	<p>Social Confidence – <i>Still feeling confidence in meeting people and new places and feeling happy and satisfied with daily activities. Feels he is on the mend and needing to push himself more as it is mind over matter.</i></p> <p>Independence and activity – <i>He is still a bit weak and still but still feels strong independence, however for the first time he has agreed in not having the thought or need to go out to work. Still does not feel a failure in what he can do and the fatigue is in control but the social life could be better. He is pushing his activities in making sure he can continue to use his limbs through his own self-determination and control. He feels his strong mental abilities with continue to drive his weakened physical limitations.</i></p> <p>Worries and concerns – <i>There are still concerns about the future and how things are slowly moving forward. He now feels he has good day and bad days and on some days needs more help and he controls that. He is worried he may not get his hand and leg movements back to what they were and how that might affect things moving forward. He keeps saying people with MS should not overdo things as MS bites back.</i></p> <p>Personal control – <i>He is back to planning the future and moving things forward at his pace and doing things with his family and friends. He feels he can do things when and how he wants to but does have to rely on more help on his bad days. He is not walking much at all now which is getting to him but he does still try. He is a very determined person who is positive, wants to be in control and values his independence, self-esteem and confidence.</i></p>

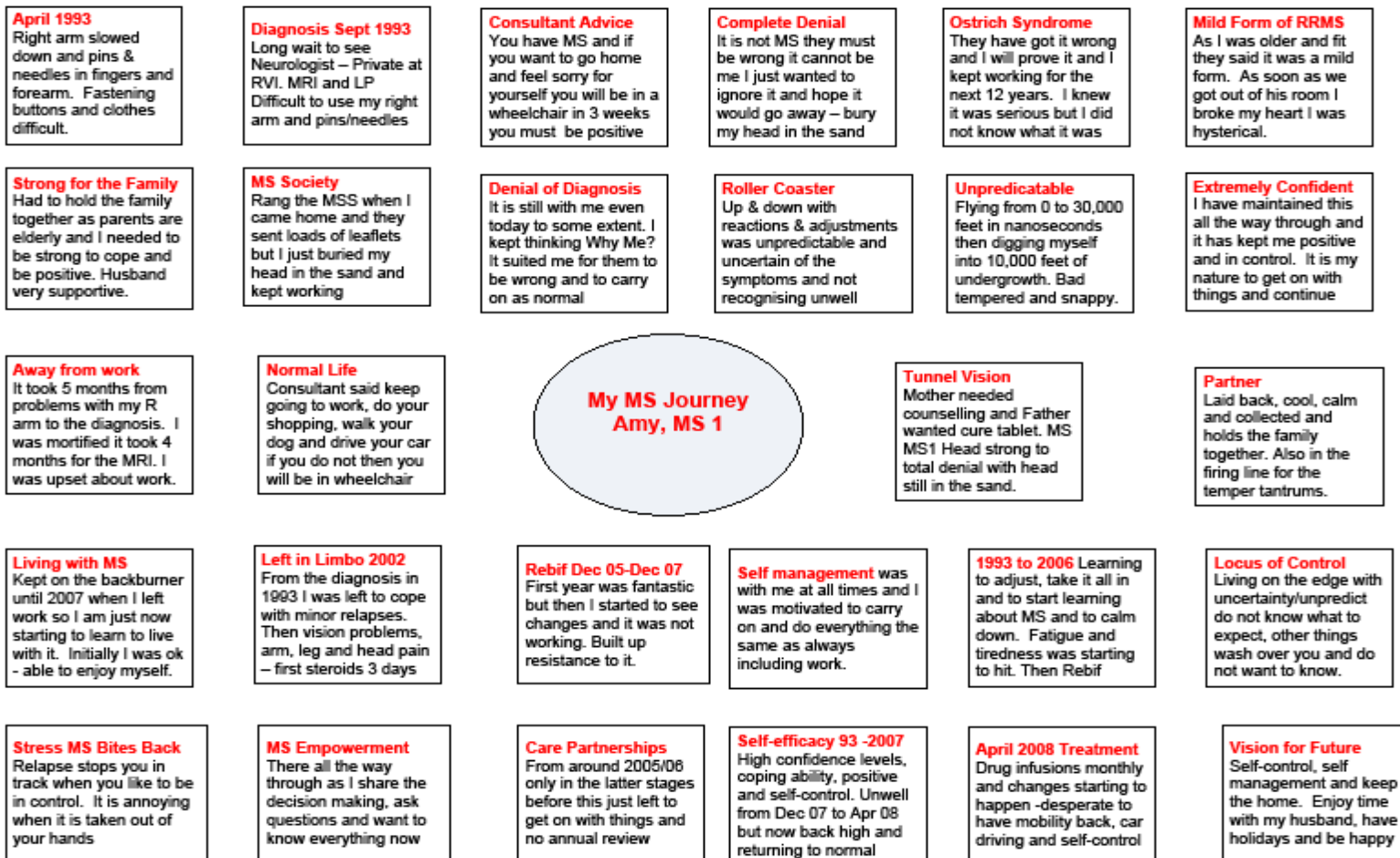
MS 6 MEETING 7	SELF-EFFICACY QUESTIONNAIRE
<p>As far as my MS is concerned my right leg is continuing to deteriorate and I fell this morning and went down and bang hit my head but did not hurt myself.</p> <p>I see myself as the same person as I was before MS and the only thing constraining me is my physical ability.</p> <p>MS does not take over me I am still in control & would not have it any other way. I am positive and determined that the physical limitations are not going to stand in the way.</p> <p>I can still do the things that I have always done & I can control that even if I do need help now to be able to do them.</p> <p>My life and family would have been the same with or without MS.</p> <p>My lifestyle has changed in terms of all the sports I was doing but it is a more sedate lifestyle but I am still in control.</p> <p>Life is for living & MS has not changed the person or the life it has just restrained me in a number of physical ways.</p> <p>I am a confident person and am sure of myself and MS or the challenges that it gives do not deter me in any way.</p> <p>It is all about pacing and being prepared.</p>	<p>Social Confidence – <i>This morning he had a bad fall but he wanted to and was determined to proceed with our meeting. He stated he was strongly confident and in control and happy with his days. Things have been ticking over nicely and his partner is on holiday and they have been having days out together which he was really happy about.</i></p> <p>Independence and activity – <i>Still feeling strongly that he has the independence he needs and again does not now want to work. He no longer feels he is a failure in things he tries to do, his fatigue is still in control and things are moving along well. The activities are increasing and he is self-managing more and doing more.</i></p> <p>Worries and concerns – <i>He stated there are things he tries to do but cannot but he times them right so he has the backup support as and when he needs it. This makes him less certain of his abilities but he says does not affect his confidence at all. He has accepted MS as part of his life but he feels it will not overtake his life as he is in control. He disagrees that MS control his life and states he will do all he can to keep it that way.</i></p> <p>Personal control – <i>Today he is disagreeing that planning helps him cope with his illness but that it is about self-pacing and being prepared as and when things happen. He feels he can do what he wants to when he wants to and can stop MS interfering in his life. His lifestyle has changed to being more sedate but he is still personally in control. He accepts what MS gives him and self manages it accordingly.</i></p>

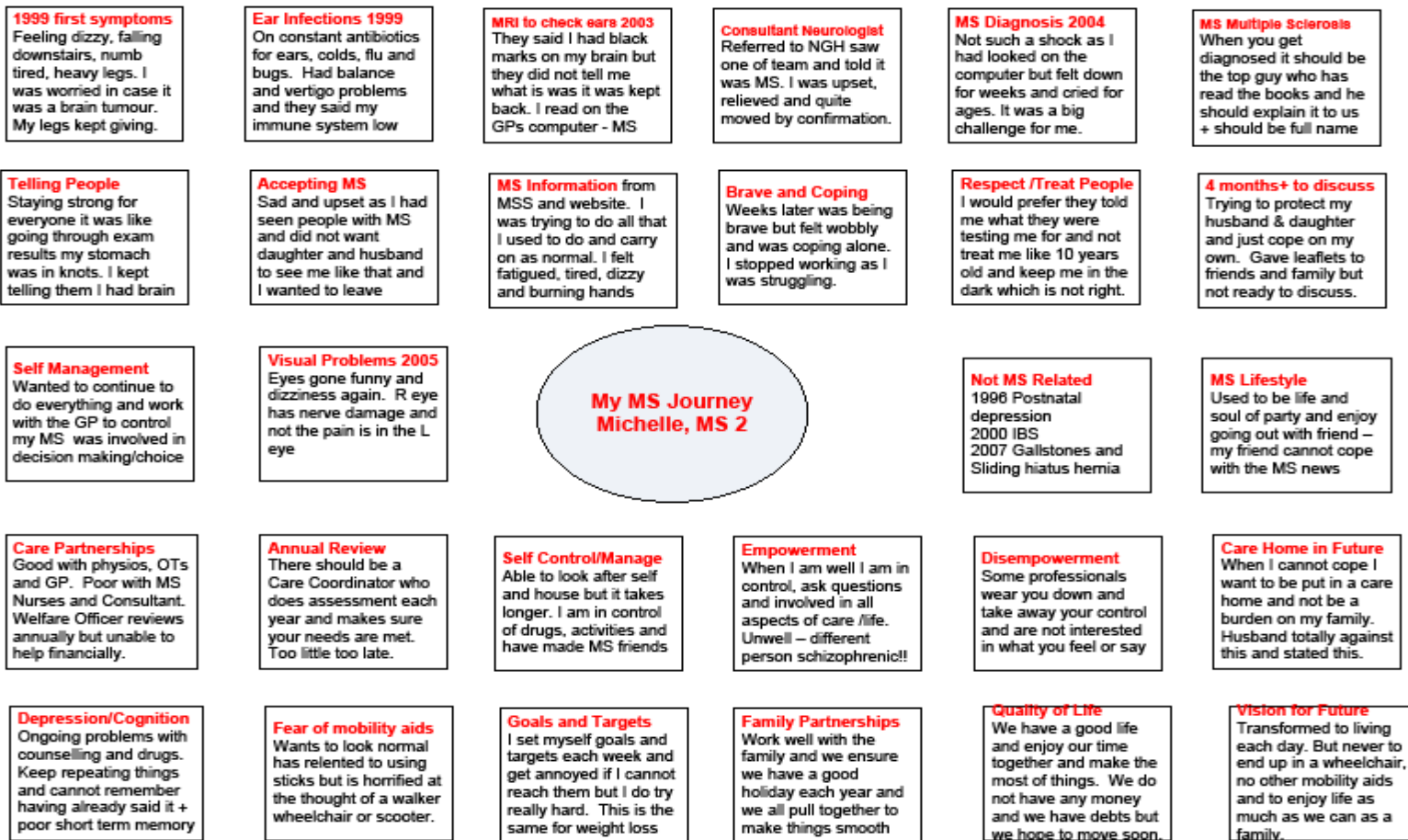
MS 6 MEETING 8	SELF-EFFICACY QUESTIONNAIRE
<p>I have no changes mentally but I am feeling changed physically with more slight deterioration but hope it will not last. I still feel good and am able to enjoy life with MS, I would prefer that I did not have it but that is one area beyond my control. I do not feel I have lost my life to MS but it is part of my life but it has not taken over. The extension is going ahead after over 2 years they are going to start next week – now that has been an uphill challenge. I am confident on what I can do, in doing what I can do and will continue to do what I can at all time. My goal is to continue to do as much for myself as I can and to keep the strength of mind to do that. I have got no fears of asking for help if and when I need it. MS does not really fit into my world I would say that my world fits around MS. MS determines the path you are going to walk down but it does not stop you taking little branches off it when you want to. I am determined by my physical limitations of MS so it controls to some extent but it doesn't totally control you—that is you. MS can restrict your freedom but not stop it.</p>	<p>Social Confidence – <i>Things are improving but he is accepting the last relapse has left some damage with numbness and deterioration in his right leg but he is again now able to walk a few steps with his crutches. He is so determined, confident and mentally drives himself in everything that he does. He is feeling happier and more satisfied with his days and can do more.</i></p> <p>Independence and activity – <i>He is back to thinking he would like to go back to work and still strongly feels he is as independent as he needs to be. He is no longer feeling a failure is what he tries to do and is showing this through what he achieves and in controlling his fatigue. He has finally been given the go ahead on his downstairs extension and he is rigorously planning things out and has high hopes for activity improvements with a wet room.</i></p> <p>Worries and concerns – <i>He thinks he will live upstairs while the work in ongoing and is planning this whereas his partner with his agreement was planning respite in Keilder Forest for him. He feels things may not have been so bad if he has this extension done earlier as the problems in getting upstairs have had an impact on his mobility and deterioration which he has been concerned about. He is feeling in control of his MS and looking forward to the future.</i></p> <p>Personal control – <i>He states the planning is helping him cope with the future of his MS and the family are working together to make it happen. His goals continue with self-management and keeping his mental strength over his physical abilities. He is as positive as always and feels MS can restrict his freedom but he will always find ways around it.</i></p>

Appendix VI

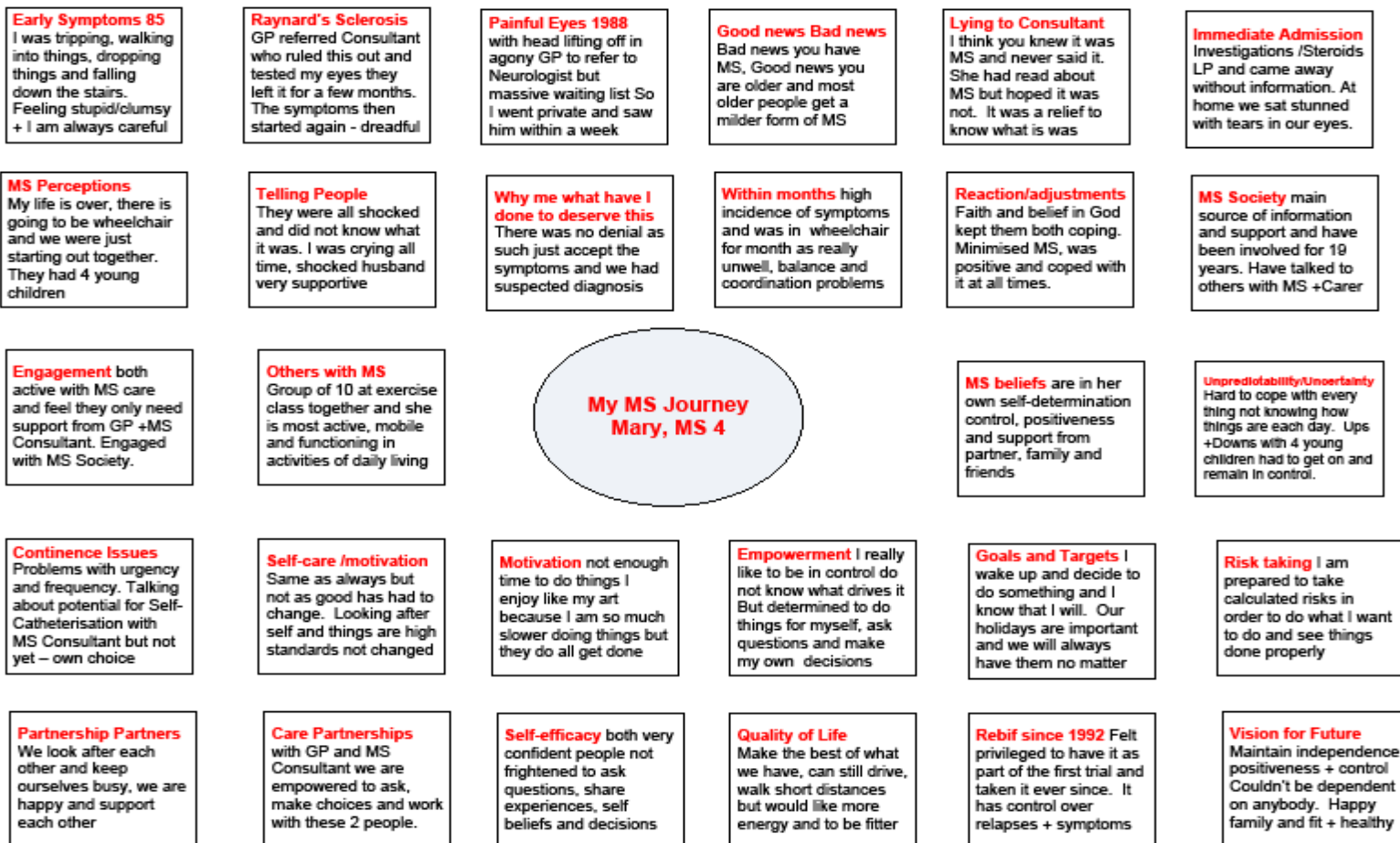
Personal Journey Maps of People with RRMS

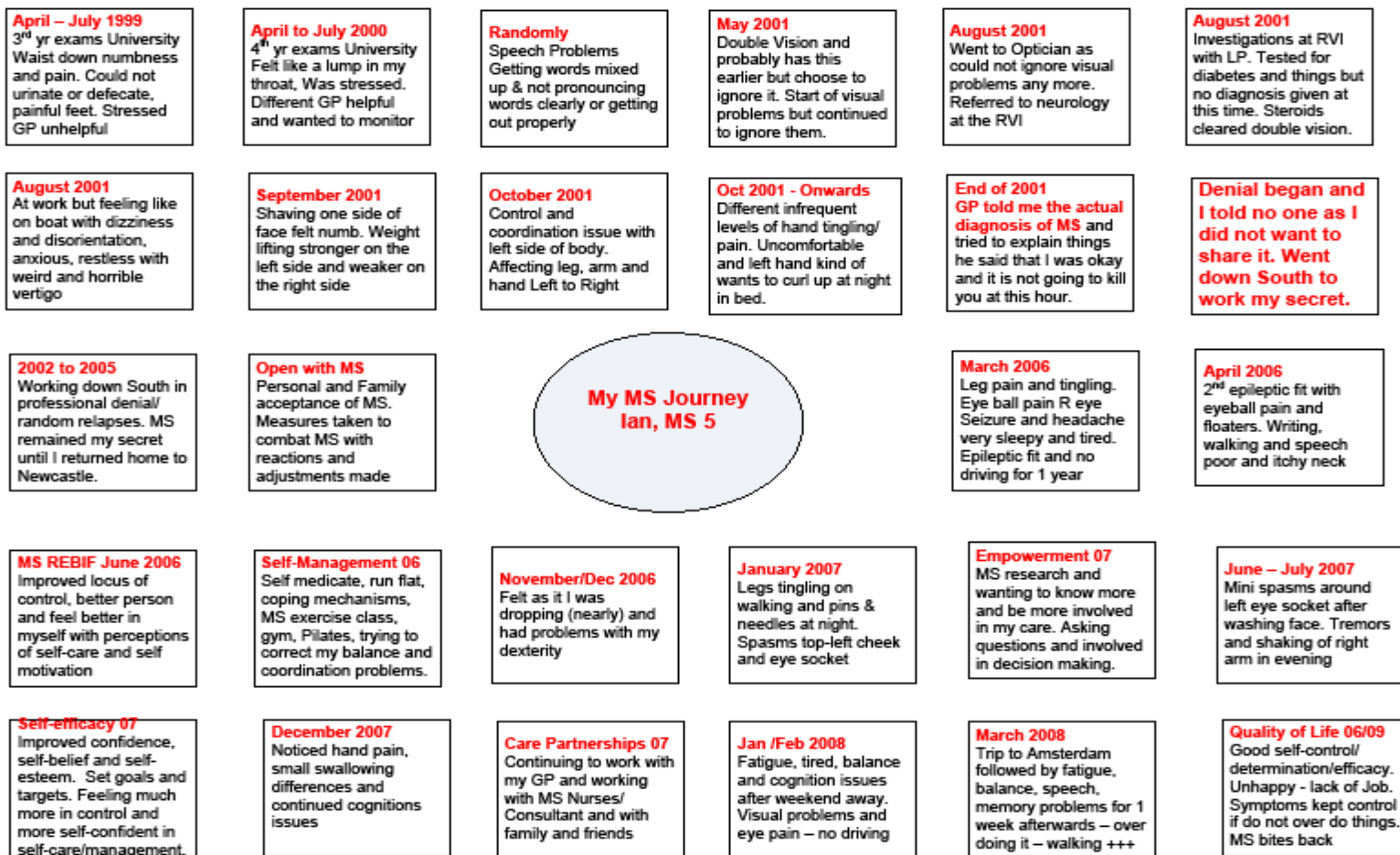
MS1 – MS6

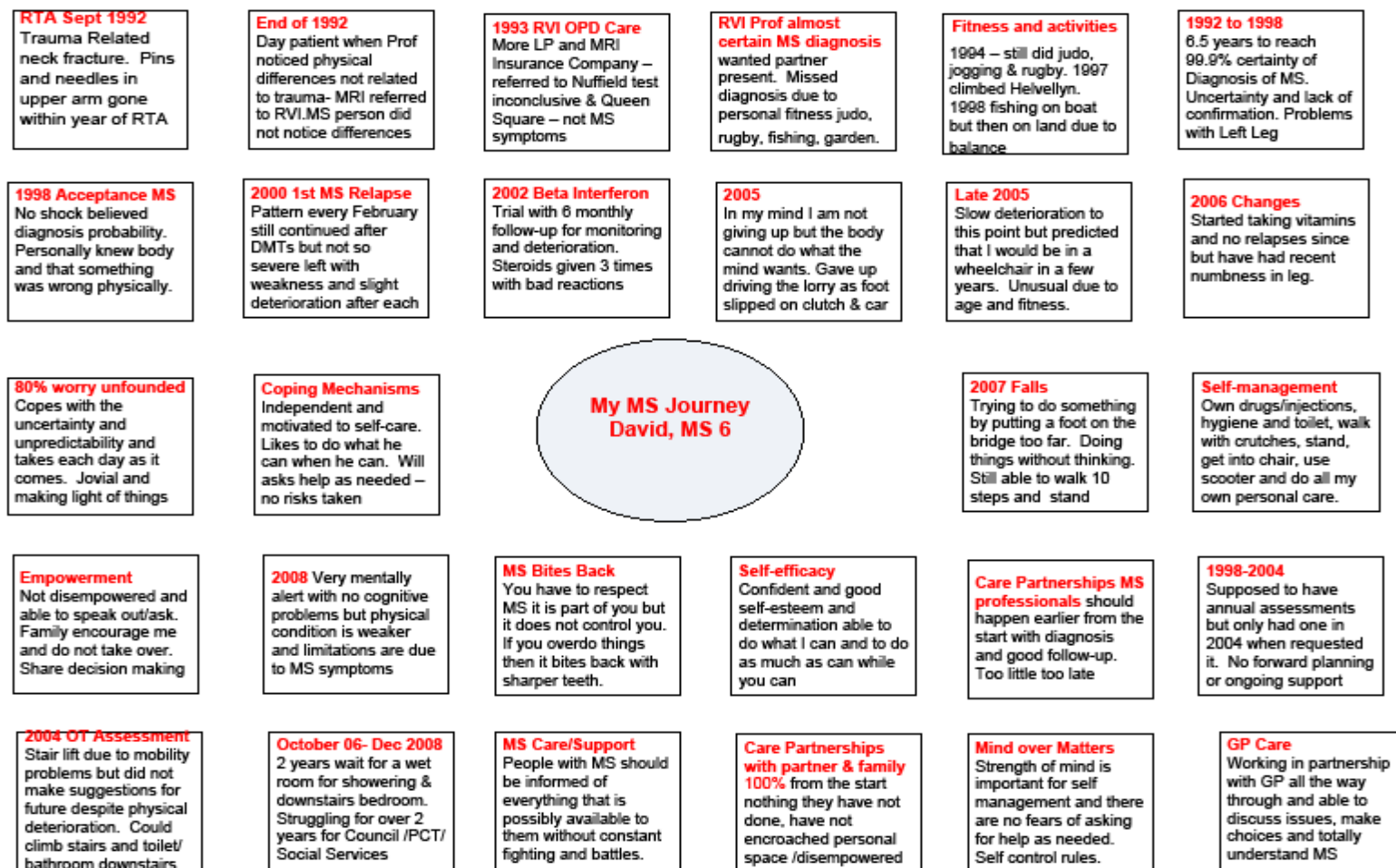












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